DOCUMENT RESUME

ED 191 813 SP 016 523

TITLE	Teacher's Guide. Starting a Healthy Family: Choosing Parenthood, Families With Special-Needs Children, Families and Futures: Helping Self and Others. Family and Community Health Through Caregiving.
INSTITUTION	Education Development Center, Inc., Newton, Mass.
SPONS AGENCY	Kellogg Foundation, Battle Creek, Mich.; March of Dimes Birth Defects Foundation, Washington, D.C.
PUB DATE	78
NOTE	101p.; For related documents, see SP 016 524-526 and SP 016 528.
AVAILABLE FROM	Education Development Center, Inc., 55 Chapel Street, Newton, MA 02160 ($4.50).
EDRS PRICE	MF01 Plus Postage. PC Not Available from EDRS.
DESCRIPTORS	Adolescents; Community Resources; Congenital Impairments; *Disabilities; *Family Life Education; *Family Relationship; High Schools; Mainstreaming; Mental Retardation; *Parent Child Relationship; *Pregnancy; Prenatal Influences; *Sexuality

ABSTRACT

This teacher's guide, part of the Family and Community Health Through Caregiving program, is designed to be used with the student manuals "Starting A Healthy Family: Choosing Parenthood," "Families With Special-Needs Children," and "Families and Futures: Helping Self and Others." This manual, designed for teaching family life education to high school students, presents learning objectives and suggested activities. Also included are teaching methods for exceptional students and their nonhandicapped peers, and a bibliography of supplementary reading materials. (CJ)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED191813

Family and Community Health
Through Caregiving

Teacher's Guide

Starting A Healthy Family: Choosing Parenthood

Families with Special-Needs Children

Families and Futures: Helping Self and Others

U S DEPARTMENT OF HEALTH,
EDUCATION & WELFARE
NATIONAL INSTITUTE OF
EDUCATION

THIS DOCUMENT HAS BEEN REPRODUCED EXACTLY AS RECEIVED FROM THE PERSON OR ORGANIZATION ORIGINATING IT. POINTS OF VIEW OR OPINIONS STATED DO NOT NECESSARILY REPRESENT OFFICIAL NATIONAL INSTITUTE OF EDUCATION POSITION OR POLICY

"PERMISSION TO REPRODUCE THIS MATERIAL IN MICROFICHE ONLY HAS BEEN GRANTED BY

Ruth MacDonald

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

Copyright © 1978, Education Development Center, Inc. All rights reserved.
EDC School and Society Programs, 55 Chapel Street, Newton, Massachusetts 02160

SP 016523

Contents

Why Use These Materials? 1

Overview of Student Activity and Materials 3

Overall Goals 6

Learning Objectives 7

Skill Development 9

To Teachers of Students with Special Needs 10

Methodology 18

Using the Case Studies 18
Using the Research and Reports 19
Brainstorming 19
Working in Small Groups 20
Role Playing 21

Before You Begin 22

Grade Level 22
Amount and Level of Reading 22
Scheduling 23
Sample Lesson Plans 23
Background Readings 23
The Glossary 23
Tapes and Filmstrip 23

Teaching Strategies 24

Starting A Healthy Family: Choosing Parenthood 25

Introduction 26
To Be A Parent 27
The First Nine Months of Life 32

Families with Special-Needs Children 38

Five Families 40
Range of Retardation 53

Families and Futures: Helping Self and Others 59

Helping Others: What Can We Do to Help? 59
Helping Ourselves: How Parents Affect the Health of Children 70

The Glossary 78

Background Readings 79

Notes From a Social Worker 79
Cerebral Palsy 81
Down's Syndrome 83

Annotated Bibliography 92

Metric Conversion Factors

Approximate Conversions to Metric Measures

Length

Symbol	When You Know	Multiply By	To Find	Symbol
IN	INCHES	2.54	CENTIMETERS	CM
FT	FEET	30	CENTIMETERS	CM

Mass (weight)

Symbol	When You Know	Multiply By	To Find	Symbol
OZ	OUNCES	28	GRAMS	G
LB	POUNDS	0.45	KILOGRAMS	KG

Why Use These Materials?

Among adolescents in the United States, the number of pregnancies has been increasing in recent years. This phenomenon, which some people have called an "epidemic," is of great concern for a number of reasons.

- One out of five babies is born to an adolescent mother. In most cases, the fathers of these babies are also in their teens.
- Babies born to mothers in their teens are at high risk for life and health. Death rates for babies born to mothers under 15 are more than twice the rates for babies born to mothers between the ages of 20 and 34.
- Mental retardation, birth defects, epilepsy, and birth injuries occur more often to children born to mothers under 20.
- Many of the babies born to adolescent mothers are unplanned, and are born into situations where there is little economic sustenance for their daily lives.
- Very young mothers have little experience in taking care of babies; there is increased incidence of child neglect through ignorance.
- In many instances, society does not accept the status of young motherhood, and therefore may not support the emotional needs of young mothers, young fathers, or babies born into these situations.

Our research has shown that young people in their teens do not often make the connection between their own sexual activity and the baby that may result. It is natural for them to be involved to some degree in exploring sexuality and establishing intimate relationships. But all too often this developmental task of adolescence overshadows the myriad practical considerations of parenthood.

Although these materials do not address young people's sexuality or sexual relationships directly, they do attempt to help students realize what parenthood entails. Parenthood, once begun, continues over a long period of time. Though it affords many joys, pleasures, and satisfactions, it also demands from parents a great deal of reliability, responsibility, and the ability to put another person's needs before one's own. We believe that the nature of adolescence in our society works against many of the imperatives of parenting. Without question it is difficult for a young person to fulfill his or her own special needs during adolescence and also meet the needs of a child.

We have attempted in the student materials to present these ideas in a positive way. Activities and readings help young people to see how other people have managed their lives. We hope that students will see that planning can lead to positive results, while a lack of planning may result in difficult times for themselves and their children. The material gives young people the opportunity to work through their own time lines and to think about the experiences and accomplishments they might want to plan for their own lives.

We do not intend to imply that there is any one right time to become a parent, or that there is any one chronology for carrying out life plans. Rather, we feel that by considering a range of alternatives and their possible consequences, young people will be helped to choose their life events consciously, rather than to feel buffeted by events and circumstances.

To underscore the responsibility of parenting, we have included significant materials on the families of children who are born with birth defects. As five to seven percent of babies born each year have defects of some seriousness, we want young people to realize that this is a possible consequence of parenthood. The impact of such an occurrence on parents can be of great concern to them. The special strains inherent in this situation are reflected in a divorce rate for this group that is double the divorce rate for the general population. We believe that the physical, social, emotional, and financial demands imposed by such children can be extremely difficult for parents to sustain.

The case studies on children with birth defects highlight the emotional trauma and coping strategies of the affected children and their parents. We hope these case studies will help young people to recognize both the community supports and resources that are available and the need for their own roles as helpers.

In many parts of the country, children with special needs are mainstreamed into regular classrooms. This requires increased understanding from classmates and others in the school and community about the feelings, capabilities, and roles handicapped persons may have.

Finally, by understanding the personal and social consequences of birth defects to families and individuals, we hope that young people will want to do everything they can to prevent birth defects. Responsible roles they can play range from being careful of their own health, to informing others about proper care, to supporting public policies concerned with the prevention of birth defects.

Because we believe that human behavior is strongly influenced by family and community environments, the materials enable teachers to explore these influences on human behavior. The materials are designed to motivate students to explore community influences on behavior, particularly the ways behavior may be affected by resources or lack of them within the community. By learning to care for and about others, we believe students can learn to care for and about themselves, and develop a new sense of responsibility for behaviors that have health consequences.

An effective approach to raising national health standards must involve a multiplicity of groups and institutions including students, parents, health professionals, schools, hospitals, and community agencies of all kinds. By involving community volunteer organizations in the implementation, use, and dissemination of the course, we can reach an audience larger than school alone can provide. We will be promoting education regarding health care on many levels.

Overview of Student Activities and Materials

Starting A Healthy Family: Choosing Parenthood

The case studies in "Ten New Families" provide glimpses into the feelings and actions of people who are dealing with the arrival of an infant right now, or who have decided not to have children. The studies provide information at a depth that students might not feel comfortable discussing in person with new or expectant parents. The case studies present real persons representing a range of ages, situations, expectations, and attitudes. Questions following each case focus students' attention on the details and themes of that particular case.

Following the case studies, Dr. Neil Macintyre of Case Western Reserve Medical School discusses the universal investment he believes parents make in their children.

The course now turns to pregnancy, the first nine months of life. This section opens with factual information on how a woman knows she's pregnant, followed by an interview with an obstetrician/gynecologist.

"Nine Months to Grow In" addresses questions students have raised about normal fetal development. Representational drawings of the developing fetus are provided along with factual information to give an idea of the complex changes that occur during the course of pregnancy.

The course begins with activities and discussions designed to help students think about their own early years. The opening activity, "Family Talk," asks students to think about how the values and expectations of parents have been transmitted to them. A second activity, "When You Were Born," invites them to discuss the personal and social environment at the time they were born. The activity asks them to consider that the environment in which people have and raise children influences both parent and child.

"The Times, They Keep A'Changin'" introduces the idea that students live in a time and place that helps to define their lives. Through the use of personal time lines, they consider what they may want to do in a reasonable future time, and decide when (and if) they would like a baby to be part of this future. By comparing time lines, students begin to see the trade-offs involved in having a baby; they can begin to think realistically about the factors they will want to consider when they decide to have children.

The "Class Reunion" role play allows students to verbalize their plans to one another—to stand outside themselves in some minimal and, we hope, non-threatening ways. Interviewing a school graduate allows them to talk with someone a few years older. This can serve to make their own futures seem

more concrete—futures that will really happen, and that may or may not involve children.

"Beginning Again and Again" is the final activity of *Starting A Healthy Family: Choosing Parenthood.* It summarizes the themes presented thus far, and asks students to reconsider if and under what circumstances they might become parents.

Through these materials, we hope students will understand that parenting is in most of their futures, and will begin to think about and plan the circumstances in which they want to be living when that event occurs.

Families with Special-Needs Children

Case studies of five families introduce students to the ways some families have reacted to the birth of special-needs children, and how they have coped with the situation once it was diagnosed.

Jenny MacLean describes how she and her husband reacted to the news that their son had been born with severe handicaps. Following this is an interview with Dr. Neil Macintyre, who suggests some ways that people can listen to and provide support for these parents.

Neil and Donna Hobson and the O'Mally family discuss how they learned to cope with the problems resulting from having special-needs children. The Hobsons have three children. The oldest child is normal, their second child has a minor defect, and their third is severely retarded. Peggy O'Mally has two siblings with special needs. She talks about how her family has helped her 13-year-old retarded sister, who lives at home, and how they decided to institutionalize a brother who is now 19.

Dr. Robert Cooke, who works with families of special-needs children, offers some suggestions to help families to cope with children born with special needs. He advises that they plan their lives one step at a time. He urges parents to have realistic expectations for their children, both those with special needs and those who are normal.

Geri describes the difficulties and rewards of taking care of her retarded daughter for 19 years. Bill and Margot Kaldma talk about their five-year-old son, who was born blind. They discuss the decisions they made and the supports they have received from friends, family, and others in the community.

The case studies are followed by data on the incidence and occurrence of retardation in the United States, and about the kinds of things that can be done by persons with varying degrees of retardation.

"Birth Defects: Why Do They Happen?" and "Inheritance: The Biological Connection" provide much factual information on birth defects. The book concludes by asking what parents and expectant parents can do to prevent or reduce the risk of birth defects.

Families and Futures: Helping Self and Others

In this book, students begin to think about the resources available to families with special-needs children from individuals and institutions in the community.

Stephen Slater is a 17-year-old retarded boy who was mainstreamed recently into a public high school. His story is told by his counselor. Mark Motta has cerebral palsy. His story is told by members of his family and a neighboring family. From these short pieces, students develop a fairly complete picture of the individuals and agencies that have been influential in Mark's life, and begin to form a view of Mark himself. At this point Mark speaks for himself, describing the needs and abilities of handicapped persons as he sees them and talking about his accomplishments and interests. A note from Dr. Robert Cooke offers suggestions on how to act with persons with special needs. This leads into an article by a teacher's aide, who describes her work in a school for profoundly retarded adolescents. The reading gives an idea of the patience and dedication such a job entails, as well as the rewards it offers.

Ellen, the teenage mother of a child with cerebral palsy, shares her history, describes the decisions she has made, and tells how she learned to find the services she needed for her daughter Cherice, who is now four years old.

The section "Helping Ourselves" focuses on ways individuals can develop sound health habits. It begins with "A New Kind of Checkup." An adolescent girl expresses her nervousness about having her first gynecological checkup. A mother tries to reassure young women that such an examination is not only important, but that their feelings and privacy will be respected by the doctor.

A major activity involves compiling a directory of community resources that serve people with special needs. Throughout, students have opportunities to consider how they themselves can aid people with special needs. You may want to review this material early on, and let students know it is coming up, so they can be thinking about it throughout the module. "A Baby's Health Is Influenced By..." provides important information and questions to support students' research.

The Glossary

The glossary in each book contains technical terms that occur throughout the course, many of which may be new to students. Students should be encouraged to refer to the glossary throughout the module, to answer questions that come up in class discussions, in the readings, and when doing activities.

Overall Goals

- To help students to think about parenting as one of the choices they will have to make during their lifetime, and to consider how they will make that choice responsibly.
- To help students gain a realistic understanding of the nature of parenthood--its costs and benefits—and to recognize it as a more rewarding activity if a baby comes into their lives when they are "prepared" (according to *their own criteria*) for its arrival.
- To encourage students to begin now to care for themselves and to prepare for having healthy families, recognizing that choices and decisions parents make even before the moment of conception will affect the health and well-being of their baby.
- To help students to realize that birth defects are a serious problem for individuals and society, and to consider how they can help people with special needs in their own schools and communities.
- To help students think about the ways they can become effective advocates for social policies that foster healthy babies, healthy mothers, healthy fathers, and healthy families.

Learning Objectives

Major learning objectives for students are listed below. Specific objectives for each reading and activity are included in the teaching strategies section of this guide.

Starting A Healthy Family: Choosing Parenthood

- To understand that parenting creates significant changes in the life/lives of the parent(s) involved.
- To understand that a significant number of adolescents are becoming parents.
- To become aware that parenting continues over a long period of time.
- To understand that parenting is a more rewarding activity if a baby comes when the parents are prepared (according to *their own criteria*) for its arrival.
- To begin to picture themselves in the role of parents.
- To gain a realistic understanding of the costs and benefits of parenthood.
- To think of parenting as one of the choices to be made during a lifetime, and to consider how to make that choice responsibly.
- To gain information about pregnancy, normal fetal development, and the feelings of the parents during pregnancy.
- To understand that a baby's health can be influenced from the time of conception.
- To understand that the fetus is most vulnerable to damage from its environment during the first three months of pregnancy.

Families with Special-Needs Children

- To realize that birth defects are a serious problem for individuals and society.
- To explore the impact the birth of a retarded child has on the family.
- To understand that adolescent mothers are at greater risk of having a child with a birth defect than mothers in their twenties.
- To learn how different families have coped with having a special-needs child.
- To empathize with families of special-needs children.
- To consider possible genetic causes of birth defects.
- To become aware of the resources—professionals, institutions, religions, neighbors, community associations, etc.—available to people with these particular health needs.

Families and Futures: Helping Self and Others

- To consider the special needs of a range of adolescents with birth defects, and how informal contacts with members of the community, neighbors, and school-age peers affect adolescents with special needs.
- To consider a wide range of society's attempts to meet these special needs, from integration into public facilities to special institutions set up especially for adolescents with severe disabilities.
- To gain understanding about how young people with special needs feel about themselves and their relationships with others.
- To begin to empathize with some of the feelings young people with special needs might have.
- To consider the special problems and resources of an adolescent parent of a special-needs child.
- To consider how to help people with special needs in their own schools and communities.
- To locate resources in the community for helping individuals with special needs.
- To consider possible environmental causes of birth defects.
- To understand that parents make choices and decisions from the moment of conception that will affect the health and well-being of their baby.
- To begin now to care for themselves and to prepare for having healthy families.
- To learn some ways to reduce the risks of having a birth-defective child.
- To locate resources in the community to meet the needs of special-needs individuals, and to compile an inventory of such resources.
- To think about ways of becoming effective advocates for social policies that foster healthy babies, healthy mothers, healthy fathers, and healthy families.

Skill Development

- To develop listening skills to aid in effective caregiving.
- To develop skills of cooperation and sharing needed to work effectively in small groups in a manner that is supportive of all group members.
- To develop self esteem and self reflection.
- To empathize with another individual or group.
- To learn to look for cues about how to respond to others, including those with special needs.
- To communicate better with friends, families, and those around them in the community.
- To increase their abilities to make choices and decisions that will lead to sound health practices.

To Teachers of Students with Special Needs

Ted Sutton works in a large public school system. He has a dual role: first as a teacher and counselor of special-needs students; second as a resource advisor for teachers within the system who have special-needs students assigned to their classes. In this open letter to teachers he gives some perspectives and suggestions to teachers who may have one or more special-needs students taking this course.

For ten years I have worked in clinics, hospitals, and public schools with children. What kind of children? When I first started teaching, they would have been called "handicapped," "disturbed" or "crippled"—in a number of senses of that word. Now these children are labeled "exceptional," or children with "special needs."

I worked for several years in settings where children were isolated from their more "normal" peers, settings which were considered therapeutic and which had school bells but locked doors. Now most of my time is spent helping to integrate these children into a public school within their own community. Despite the changes in philosophy and in language over the years, the one thing which has not changed is the children themselves.

The Special-Needs Student

The problems which have singled these children out for my attention are diverse: they may be hyperactive, depressed, blind, or deaf. They may be mentally retarded (the newest euphemism for this is developmental impairment) or have cerebral palsy. For these reasons, they have been assigned to me for individual help.

Despite current enlightened legislation and attitudes, these children are different from most of their classmates. It may be easily observable (you'd spot them as soon as you walked in a room) or it may be less obvious and require closer observation. But the children themselves have known it for most of their lives, and they'll be feeling it in some way when they walk into the public school for their first day of class.

Think of your first day at school in September, when you greet your new students. Most teachers, no matter how experienced they are, feel some anxiety. I for one always make sure that my shirt matches my pants and that I haven't skipped a belt loop. Later on in the term it won't matter so much, but on that first day I want to make a good impression. And for the special student, that impression, especially the first, is extremely important. Like most adolescents, he's extremely concerned with questions of body image. He wants

to be like other kids as much as possible, to fit in and to be regular, and yet he knows he's different. He's been told in many ways, some of them brutal.

I've observed that most adolescents who are physically or emotionally different have devised their own style of dealing with this difference. Even if their parents have been afraid to deal with it and the problems it creates, the children (while also being afraid) have somehow managed to develop a method of handling it, because ultimately they are the ones who have to live with it. And all too often they live alone with it. Through trial and error, they develop a style which protects them and which allows them to cope. Each individual's style is different, although one can observe patterns. Here are three examples of students I have worked with which I will share with you.

Charlie

Charlie is 16. He was born with a cleft palate, a hare lip, and a number of scars on his face. These were not treated until he was placed under the custody of the state when he was ten. By this time it was impossible for him to undergo the corrective and cosmetic surgery which might have been done successfully at an earlier age. Now, after four operations, his looks have improved considerably, but he still appears deformed. His teachers characterize him as a "smoothie" and a charmer who, despite a strong speech defect, can dream up the most exotic of excuses. Charlie is difficult to track down. He always seems to be on the run—seldom where he is supposed to be. He fantasizes about affairs with movie stars and being a millionaire. He can rarely deal with anything that is future-oriented. When confronted, Charlie is apologetic and sweet, and will say anything that will temporarily get him out of trouble.

Doreen

Doreen is 15. She is moderately retarded. "I'm sorry," or "It's all my fault" are the phrases that she's especially noted for. Her parents have had trouble dealing with her limitations and have pushed her beyond her capacity. She will often walk with her head down and mutter to herself. Sometimes she will look up and, when seeing a teacher, automatically ask "Did I do something wrong?" At times she will affect the air of a much younger child and sing aloud or giggle to herself. When upset with herself (or with others), she may start to cry. "Oh I wish I were like all of them" she'll say, while pointing her hands to all those nameless "regular" students in the world. "I just want to be, oh hell, what'd you call it? 'normal' and have a boyfriend and be happy."

Steve

Steve is 15 and has been labeled "hyperactive." Since he began kindergarten he has had difficulties at school. Teachers complain that he cannot stay seated, is always drumming his fingers, making sounds and being distracted. Other students accuse him of teasing and being a nuisance. Steve often tries to monopolize classroom discussions and demand special help from the teacher, even with tasks that he knows how to do. He has made a name for himself at the school by running through halls, hitting, and poking smaller children. Medication has been helpful in that he seems calmer (i.e., slower and quieter)

and spends more time in class and out of trouble. What teachers and students don't know about Steve is that he was adopted at three and walked in on his mother (three years ago) after she had committed suicide.

Now he lives with his father, and the family seems to be engaged in one crisis after another. His situation has been anything but stable. Steve seems to be rather desperately crying, hitting, begging for attention, for limits and for help. He is literally being expected to sit on much of his anxiety and his disruptive actions might be looked at as simply means of blowing off steam or reducing the tension which is so much a part of his daily life.

Steve once went to a special school but begged not to be sent back as the more disturbed children he was with frightened him, and he feared that he might get to be more like them. Despite his flamboyant mannerisms and style, he can verbalize his desire to have friends and do well. But he also has a need to be punished and singled out (one mother gave him up for adoption, another destroyed herself). On some levels, he must be blaming himself and wondering what he did to make them abandon him. This is his dilemma; this may be why he behaves the way he does.

Developing Relationships

At times, it's been difficult for me to develop working relationships with students such as Charlie, Steve, and Doreen, as much of their personality is built upon styles which emphasize characteristics such as self-denigration and evasion—characteristics I consider negative and self-limiting. I have learned, however, to respect the importance of these styles and manners of expression to the children I work with. They've protected themselves in these ways for so many years. Such patterns didn't simply spring up out of nowhere.

Charlie, Steve, and Doreen have been in dozens of situations with hundreds of strange people, and I can appreciate the struggle it has been for them to somehow try to emerge whole. They want to be "regular," just like their classmates and yet they know (as none of us can know) what it is to hurt and to be unable to understand the hurt. They know they're different and they want this difference to be acknowledged, especially by those they look to for support—such as you, their teachers. How it is acknowledged, especially at the beginning of a relationship, can determine their success in your class.

You can represent many things to them: a role model, a limit-setter, and an understanding adult working in alliance with them. While each special student is different, it is possible to make generalizations and to offer some strategies and approaches which might be considered, attempted, or discarded according to your experience and intuition.

How to Proceed

If you've had some warning that a new student in your class may be special in some way (e.g., deaf or disturbed), try to sit down with the child *before* his or her first class. You might want to invite a counselor or someone who knows

the child to be present. These persons might make the meeting less anxiety-provoking for the student.

The meeting should not be long—perhaps just a few minutes. But you might let the student know several things: first, tell him who you are. It will be a lot easier for him to walk into that opening class if he's met you and knows that you know him. Second, you could share some of your expectations. These could be about work or behavior. If the situation is particularly loaded (such as when talking with a hyperactive boy about your rule that students raise their hands, when you know very well that he has a history of screaming and swinging from the ceilings), simply be matter-of-fact and do not necessarily overwhelm the child by the fact that this might become an issue. An expectation of behavior all too often becomes predictive of behavior, and a child is not given a proper chance. For this reason, even if you're not too excited about having this particular student in your class, it's wise to be as optimistic as possible in your meetings. It's extremely helpful for special students to know that if they have trouble with the work they can see you after class, that you can make some blocks of time for them. Even if this is never necessary, it will reassure the student to know you will be willing to meet with him "just in case."

It might also be wise to acknowledge to the student that you are aware of his unique problems. This can be done in a simple and positive way. For example:

> "I know that you have problems seeing, so it might be best if you sit in the front row."
>
> "I'm glad we're having this chance to meet before class. Since you have cerebral palsy you might have some trouble getting around the halls and might be late for some classes. What can *we* do to make this easier for you."
>
> (To a slightly retarded girl.) "I know this is going to be a new kind of class for you. Sometimes you won't get a chance to remember everything. You can always see me after class. I'll repeat anything you want me to."

It's important that special students have an initial "honeymoon" period during which they feel protected and cared for. This does not mean that expectations shouldn't be spelled out or limits set. Consistency should always be stressed, but it might be best to wait a week or two before asking these students to speak or perform in class.

It's sometimes easy for teachers to be so sensitive to certain students' needs that the students' intellectual development is inhibited. After a relationship has been established, encourage, urge, and if need be, push these students to accomplish as much as they can. "I can't," often means "I can't do it *this way*."

And the Rest of Your Students?

Often, if a special student is entering a class which has been meeting regularly, it is helpful to spend some time discussing the situation with members of the

class. A special student will experience an easier transition with the additional support of your existing groups. The difficulties he or she is having will be greatly multiplied if your class feels hostile or threatened in any way.

I've found that it's best to mention a new student's arrival the day before he or she is to show up, and to be as brief as possible when discussing it. Realities should be readily acknowledged, and it is best to be matter-of-fact and deal with the student's problems in understandable language. For example, you might say:

> "Tomorrow a new girl will be in our class. She has cerebral palsy. She has trouble walking and uses crutches. Sometimes you'll see her hand shaking a little."
>
> But remember to be reassuring and, if necessary, stress that "it's no big deal" and not contagious.
>
> "It doesn't mean she's hurting or needs help. She'll stop shaking in a minute or two. She was born with this disease. It's not something you can catch."
>
> If you can form a partnership with your class, all the better:
>
> "Look, I'll level with you, it might make things a little different at first for you, as well as me. But I'm sure once we get used to the changes, it will be a good experience for all of us."

Every group is different. We all have our favorite classes. How well you know your group and can plan for possible difficulties will determine much of the success of your special student. There may be one or two students who will pose special problems. Teasing, namecalling, scapegoating are already problems in many classrooms. It's not pleasant to worry about what might happen with the rest of your students when also faced with the prospect of dealing with a particularly needy child. One cannot help but wonder why children and groups of them often seem so cruel when confronted with disturbed, retarded, or physically impaired children.

One of the reasons may be that for a number of years special children have been more isolated than they are now. Their classmates in public schools are not used to seeing or being with them. What should be a natural mixture of like and unlike children is instead (at first) perceived as unnatural, strange, and startling. The classmates of special-needs students are not used to them, and their suspicions may be increased because they are in the midst of adolescence, that developmental stage when conformity is such an issue. Students who deviate from their notion of normalcy are often targets of jeering and scapegoating. If for nothing else, such actions create a sense of group cohesiveness and provide a simple way for defining (for oneself and for one's circle of friends) just what is considered important to one's identity.

The issue is not simply a matter of learning tolerance and respect; these virtues might be considered to be luxuries by teenagers. Most of them are just too busy

making gestures and decisions as well as taking stands, based on their own needs which seem of primary importance.

Some of your students may have brothers or sisters or other relatives who have special needs. Perhaps it is an aunt or uncle whom they've never met. There might be a history in their family which has not been dealt with. The newcomer to your class might thus force them to confront issues which have been neglected. And the presence of students with special needs serves as a reminder.

For these reasons the teacher must be sensitive, not simply to the new special student, but also to the other members of the class. They may need reassurance, both as a group and as individuals. The behavior which we may consider so obnoxious and negative is not simply insensitivity and cruelty on their part, but is often a way of dealing with their own tensions, ambivalence, and uncertainty.

We are all too familiar with the epithets: "retard," "freak," "queer," "crazy." What is important to remember is that they are usually not being bandied about simply for the fun of it. Essentially, they are ways particular individuals choose to cope with strange behavior or strange physical characteristics which frighten them. It is our job to allow for more understanding as much as we possibly can, so that this sort of behavior is not as necessary. We must thus provide alternatives.

Positive Alternatives

The reason behind providing alternatives is both humane and selfish. In many instances, the philosophy of singling out a special child and educating him with "his kind" is inherently limiting. When grouped together in a small classroom, hyperactive children learn not simply from the teacher but also from each other. Therefore, it is difficult to show them effectively that their style of behavior is considered inappropriate, and will not get them the kind of attention that they want. In many instances they are rewarded by their peers for acting out. In large residences and hospital settings for the retarded and physically handicapped, children may learn to respond to a society which is all too often based on management and bureaucratic regulation rather than on growth and learning. Children learn to get along in these structured, artificial societies, but once outside in the "real world" they are often helpless.

By providing space for these students in our public schools, we are offering them another chance to extend their boundaries and realize more of their potentials. This is not to say that all of them can benefit from that chance. For the more seriously disturbed or profoundly impaired, it may make no sense to place them in an integrated setting. It may be damaging both to them and to those children around them. But for many it is a positive opportunity for growth and they have a right to it.

It can also be a positive experience for the other members of your class. They can begin to understand and to practice values which before had only been addressed to them in general terms. They can begin to realize that what may be perceived as a defect is not as catastrophic as they had imagined. The inability

to walk does not preclude the ability to work, to share, to appreciate, to care for others, and to hope that those others may care for you. In some instances students may, through exposure to a handicapped child, begin to have perceptions which will heighten their own consciousness: seeing a particularly expressive painting created by a deaf girl, hearing a retarded boy play a Mozart sonata. These are instances when, as a teacher, I've felt a certain sense of privilege and awe in observing the richness of the human experience.

How About You?

It is not only important to pay attention to the needs of your special students and of your regular students, but to acknowledge your own needs as well. It's important to be realistic. No matter how caring or democratic or understanding we are, the arrival of a special child in one's classroom creates problems. Whether you've been teaching for a few years or for many, it would be difficult (in some cases impossible) to deal with these problems by yourself. You need resources, too.

Some school systems are fortunate in that they have a variety of people to whom you can turn: special counselors, consulting psychologists, psychiatrists, social workers, etc. They can provide you with support and understanding. At times, when discipline problems come up, it might be necessary to talk things over with a principal or housemaster. This does *not* mean that you are incompetent to handle things by yourself or that your judgment is in any way suspect. It simply is a means of checking yourself and allowing yourself distance. It's difficult when you deal with an issue every day to keep a perspective on the situation, to see progress which might have been made or to detach yourself enough to bring things more clearly into focus. You shouldn't expect too much of yourself.

Often we attempt to deal with an issue as if it is entirely our responsiblity, assuming no one else would understand the situation. Sometimes these things may be true. There may actually be no place to go and no one to share the problem with. Usually, when problems come up, it's best to talk to someone—a friend or perhaps another teacher you see during the day. Keeping all your concerns, fears, and anger inside does nothing more than build an illusive sense of martyrdom and make your work more difficult and less rewarding.

Sometimes it is difficult to appreciate the experience of having a special student in your classroom and to acknowledge the possible value of it. Once time has passed, it's often easier to value the process and the intricate dynamics involved.

When Doreen (the retarded girl I referred to earlier) first began attending classes at public high school, her immaturity and silliness attracted a considerable amount of attention. A certain group of boys began teasing her. "Hey, Doreen," one boy would say, "maybe you'd like to go out with my friend?" Doreen would then giggle and ask, "Oh, you think maybe he likes me? Gee, it would be nice to have a boyfriend. Do you think he thinks I'm pretty?"

Doreen would begin to initiate encounters such as these and begin to provoke older boys whom she had never met. It took several months of weekly meetings with a school counselor and sessions with a psychologist for Doreen to begin to be able to see the situation more for what it was and to be aware of her feelings that she really did want to have a boyfriend and maybe there were other ways to go about it. She could then realize, "Aw, you're just teasing me," in a very real sense of the word. And the group of four boys who were doing the teasing began to see Doreen in another manner. Sure she was viewed (among themselves) as a "retard," but they began to treat her almost as they would a younger sister. When they heard that a new student at the school had been approached by Doreen and was planning to see "how far he could get with her" they found out his name, introduced themselves to him, and explained that they were Doreen's friends and if he tried to start anything with her, he would be very sorry. The new student got the message. Both for Doreen and the group of boys, this evolving relationship allowed them a chance to grow; but it would have been difficult to realize this by observing it from the perspective of just one week.

As much as we'd like to, it is often impossible to speed up this process—this procession of students with different kinds of needs, with different potentials for growth. By preparing ourselves and our classes beforehand, and by realizing that the problems which crop up are not necessarily mistakes or anyone's fault, but stages to be passed through, we can make this necessary transition more direct and fulfilling for all of our students and for ourselves.

Methodology

We have used several pedagogical techniques in this program, each designed and implemented for specific purposes and with particular goals in mind. All teachers may not be equally familiar with these techniques. Therefore, we include brief descriptions of them below.

Using the Case Studies

Each person is a truth.
—Dr. George Goethals
Department of Psychology and Social Relations
Harvard University

A case study is a unique source of data that enables the reader to gain greater insight into human feelings, motivations, and values. It is a report (either written or oral) by an individual on something that actually happened—something that he or she felt or experienced. It is spoken or written from a first-person, "you are there" perspective.

Students who have used the case studies in this program in trial tests frequently have commented on their special evocativeness:

> "I think it was the way she talked—like she got really involved, she really got into the situation."
>
> "We put ourselves in her position, you know, and how we would feel about it. So it really got to us."

Interpreting a case study, then, involves the reader in attempting to understand the concerns, motivation, actions, and feelings of another person.

Understanding the inner workings of another human being on the basis of a limited number of pages of information may seem like an impossible task at times. But so many aspects of behavior are shared by all of us that it is indeed possible to gain some clues about another person by using the observations and conclusions we all make every day of our lives. It is important for students to remember, however, that using their own experiences and understandings will provide only clues, rather than definitive explanations, for another person's behavior. Students will never know all the "facts" in a case study but they will be able to make some good guesses and hunches.

Throughout the program are exercises and activities to help students utilize case-study data effectively. They highlight the affective dimension of case-study materials, and help to stimulate student involvement in various issues. They are also intended to help students understand what a case study can and cannot tell them about another person's behavior and feelings. They are discussed in detail in the teaching strategies section of this guide.

Using the Research and Reports

Research reports in *Starting A Healthy Family: Choosing Parenthood* give data perspectives on the materials surrounding them. If students are intrigued by the information, they could pursue the research. Students can be apprised that careful research studies are structured in the social sciences field and conducted and reported upon in much the same way that hard science data are reported.

Brainstorming

An activity that calls for brainstorming is more than just an open exploration or discussion of a problem. Brainstorming is a way of stimulating creativity and novel ideas about an area of interest. The objective is to generate as large a list of responses as possible in a short period of time.

The first activity in these materials asks the students to do some brainstorming (see "Family Talk," page 5 of *Starting A Healthy Family: Choosing Parenthood*). Before doing this activity with your students, you may want to go over the purposes and rules for brainstorming.

Purposes

- To generate the largest possible list of responses.
- To put together the list of responses as quickly as possible, while the enthusiasm of the group lasts, without evaluating or commenting on any item.
- To give everyone a chance to contribute ideas without worrying whether his or her response is carefully thought out, or repetitive.
- To make each member of the group feel comfortable about contributing ideas, regardless of whether the ideas represent his or her own feelings or are simply ideas that the contributor wants to see considered as part of the total list.

Rules

- One person serves as the recorder.
- Anyone in the group may say whatever he or she wants, as long as it's an item to be put on the list.
- Items are listed in the order given; no responses are eliminated or commented on, even if they do not appear relevant.
- Items may be mentioned several times.
- You should move along quickly.
- When nothing more is offered, allow time for silence and reflection. More ideas may be forthcoming.

Before beginning any activity that calls for brainstorming, clearly state the purpose of the specific activity. The purpose may be simply to gain an

understanding of the wide range of possible answers. Or it may be to solicit ideas about solving a particular problem or to achieve consensus about the best answers to the initial question.

After students have finished brainstorming, you may want to give them a chance to check off the ideas they consider to be most important and to discuss the reasons for their selection. As an alternative, you may wish to select themes from the larger lists. For example, in the "Family Talk" activity, you might examine the lists of specific responses to the six phrases, and explore what *kinds* of values and expectations are being transmitted by particular statements. Students may thus be helped to perceive themes and patterns that they might have otherwise ignored.

Be sure that the purpose of the brainstorming activity is understood by all participants before beginning. It is important to discuss whatever summary interpretation is made of the brainstormed list, so that the group does not feel it has gone through the effort for nothing. When managed wisely, brainstorming activities can be very useful teaching aides.

Working in Small Groups

Working in small groups allows students to select specific areas of a subject that interest them, to examine in greater depth. An example of one suggested small-group activity in these materials is "Ten New Families" (p. 10 of *Starting A Healthy Family: Choosing Parenthood*).

Before students divide into small groups, be sure that they understand the following:

- How much time will be allotted?
- Will students be assigned to groups or will they be able to choose their own groups?
- Must each group cover a different topic? Or may more than one group deal with the same subject?
- Should each group keep a record and select a recorder? After the activity, how will the groups use the work they have done?
- What role will the teacher take? Will the teacher take part in one group, drop in on each group, or stay out of discussions unless requested?
- Will there be a general sharing of ideas? Or will the recorder report to the larger group?

After completing the group activity, the class might wish to discuss how well the group members worked together. Did everyone have the opportunity to contribute? Did one person dominate discussions? Was the group sidetracked from the chosen topic? If there were recurrent problems, the teacher might discuss ways of restating the ground rules for group work, and ask the groups if they want to try working together again. Occasionally students like to redo group activities, so that they have a chance to work in a different group than the one they first selected.

Role Playing

In role playing, students are asked to pretend they are someone else, or to play themselves, in a situation that has never really occurred in their own lives. The objective is not to create a dramatic presentation. Rather, it is to have the students attain some degree of empathy with the persons they portray, and to act out, for themselves and for the rest of the group, the way they feel those people would act in a given situation.

"Your Class Reunion" (see p. 12 of *Starting A Healthy Family: Choosing Parenthood*) calls upon students to role play. In this activity, students work in pairs, each taking turns playing two roles: They try on the roles of (1) an interviewer and (2) themselves ten years from now.

Students may suggest subjects they would like to role play or would like to see enacted by others. For instance, when discussing the cases dealing with different parents' discovery that their children have birth defects, students may find it useful to role play a set of parents and the doctor who informs them of their child's problems. This exercise might help them to explore how all of the people involved might be more helpful and sensitive to each other.

In some role-play situations, the person and his or her way of thinking may be so clear to the students that there is no need to define the role. In others, it may be helpful for the class or small groups to work out role definitions for each role player.

After a role-playing activity, the group will need time to discuss what they have seen, heard, and felt. If people have different ideas as to how the role might be played, the role play might be repeated, with different students taking over the roles.

The teacher may wish to let the role play end naturally or may choose to stop the action at an appropriate time—when the point has been made, when the role players have digressed, or when it appears that nothing new will be gained by continuing.

Before you Begin

Grade Level

This material has been developed for students in grades seven through twelve, as well as for adult groups. Teachers may wish to adapt suggested teaching times and specific activities to the different ages, abilities, and interests of the group members.

Amount and Level of Reading

Some of the materials in this course may be at a difficult reading level for students in the grades for which the course is intended. Some materials, such as case studies, are in the original words of the person interviewed. Generally, students like experiencing the flavor of the person's everyday speech in the cases. However, this "flavor" does make the cases more difficult to read, because people do not always speak in full sentences, complete their thoughts, or make grammatical sense. Technical sections, such as the material on inheritance or some of the research reports, have been written as directly and simply as possible. Although technical terms have been explained in the margins and in the glossary, some materials may still be difficult for some students to read.

In working with case materials, it may be helpful to give the class a brief description of each case and allow students to read the case or cases that interest them most. For students who need additional help with reading, some teachers have had those cases not already on audio tape read aloud, either by students or by themselves. These readings may be done before the entire class or in small groups. An alternative is to have a student volunteer to read a case onto a cassette. Students who wish to hear that case may listen to the cassette in class, or may borrow the cassette to play at home. You might mention to the students that due to technical difficulties with the original recording, the "Anthony" tape in *Starting A Healthy Family: Choosing Parenthood* was rerecorded.

With the more technical sections, it is usually helpful to break the reading down into small segments. These sections can be assigned one at a time, as homework, or read in small groups during class. If the reading is done in small groups, the class can reassemble for a general discussion and sharing of what they have learned.

It can also be helpful to bring in speakers to discuss issues raised in the materials. You might wish to give the speaker the student materials ahead of time, to use as a basis for outlining the issues he or she will cover. A speaker will most likely expand on a subject and answer questions. Consequently, students may gain a greater understanding than they would by simply reading an article in class.

Scheduling

The materials have been designed to be completed in a half-year course, consisting of 30 to 35 sessions of about 45 minutes each. With this framework in mind, time allotments are suggested for each activity. You may wish to change or modify these times based on your own teaching schedule and your knowledge of your students' interests, abilities, and needs. We suggest you read the entire teaching strategies section before deciding on the schedule most appropriate for your class.

Sample Lesson Plans

In many cases, detailed lesson plans have been suggested for 45 minutes of class work. These time blocks indicate how a session might be broken up to accomplish the goals of the materials and to include a variety of activities. Feel free to modify or change the sample plans to fit your own time constraints and objectives.

Background Readings

At the end of this guide, we include a number of background readings. You need not read all of them. They are intended for reference as appropriate. You might wish to share some readings with the whole class, or with individual students or groups working on particular subjects or projects.

The Glossary

Definitions of technical terms used in the student books appear in the glossary at the end of each book. Encourage students to refer to the glossary when they have questions. For example, students might find it valuable to read the glossary entry for Down's Syndrome when discussing the Jenny MacLean case study in *Families With Special-Needs Children.*

Tapes and Filmstrip

The following audio tapes accompany the student material in *Starting A Healthy Family: Choosing Parenthood*: *Cheryl* (15.06), *Sam and Rebecca* (14.00), *Anthony* (8:04), *Carla* (13:30), *Linda and Ron* (5:30), *Jim and Mary* (11:20), and *Bob and Diane* (12:30). The numbers in parentheses indicate the time in minutes and seconds of each tape. The following tapes accompany the student material in *Families with Special-Needs Children*: *Bill and Margot* (18:13), *Neil and Donna* (8:05), and *Geri Gable* (6:35). The filmstrip *Geri* is also used with this book. The tape for *Families and Futures: Helping Self and Others* is *Ellen.*

Teaching Strategies

Starting A Healthy Family: Choosing Parenthood

Families with Special-Needs Children

Families and Futures: Helping Self and Others

Starting A Healthy Family: Choosing Parenthood

Through activities and first-person case studies, students explore the impact a new baby has on different families. They consider if, and under what circumstances, they themselves might become parents.

Learning Objectives

- To understand that parenting creates significant changes in the life/lives of the parent(s) involved.
- To understand that a significant number of adolescents are becoming parents.
- To become aware that parenting continues over a long period of time.
- To understand that parenting is a more satisfying activity if a baby comes into their lives when the parents are prepared (according to *their own* criteria) for its arrival.
- To begin to picture themselves in the role of parents.
- To gain a realistic understanding of the costs and benefits of parenthood.
- To think of parenting as one of the choices to be made during a lifetime, and to consider how to make that choice responsibly.

Possible Class Sequence (11 classes)

Class 1	Introduction
Classes 2-3	When You Were Born
Classes 4-5	Time Line to the Future
Classes 6-7	Your Class Reunion
Classes 8-10 (possibly 11)	Ten New Families
Class 11	What Parents Expect (10 minutes)

Introduction

The introduction sets the tone for the first few days of the course, and presents themes that will be discussed throughout the materials.

Have students read the introduction, "Families and Their Children." You might read it aloud or have one student read it aloud while the rest of the class follows along in their books.

The definition of "parent" is rather complicated. Students might like to discuss briefly the kinds of family structures into which a baby might be born.

Family Talk (35 minutes)

Materials

- Student book, p. 5
- Newsprint
- Marking pens

Purpose

- To think about how parents transmit values and expectations to children.

Description

This opening activity is intended to be fun. It's an opportunity for students to complete six quotes with some of the comments their parents make. As students discuss their feelings about family life, they will realize that such encounters, which often seem annoying, are examples of how values and expectations are transmitted from parents to children.

Planning Ahead

At the end of this class, tell students about the collage, "Our Beginnings," which they will begin to work on during the next session. Ask them to start collecting newspapers, magazines, and other items that describe the era in which they were born.

Procedure

Completing the phrases as adults might (10-15 minutes)
First ask students to complete the six phrases in "Family Talk" as they think *adults* would complete them. They may want to add other phrases to this list. The phrases can be completed in a variety of ways—there are no right or wrong responses for any phrase. Each phrase should be noted down on newsprint.

Brainstorming responses (10-15 minutes)
Next ask students to think how *they* would respond to the adult who made each of these statements. You might have students do this activity in small groups, each group dealing with one phrase, or have the class as a whole brainstorm possible answers. (See "Brainstorming, page 19 for tips on facilitating responses.)

Discussion could then focus on the specific values adults seem to be expressing in these statements, and on whether their children seem to be accepting these values and expectations or formulating new ones of their own (as indicated by the responses students made to these statements).

Summarizing (10-15 minutes)
To summarize the discussion, you might write these three phrases on the board or on a piece of newsprint:

- acceptance of values
- modification of values
- substitution of values

Ask students to look back at the phrases they have just completed and suggest a few examples of the three phrases you have just written down. Write their responses on the newsprint. Save these sheets to use again in the activity, "Our Beginnings."

To Be A Parent

When You Were Born (2-3 classes)

Materials

- Student book, pp. 7 - 8
- Newspapers, magazines, music, and other "artifacts" from the year most students in the class were born
- Newsprint or construction paper, scissors, glue, scotch tape, etc. for constructing the collage

Purposes

- To think about the social and personal context into which students were born.
- To begin to consider the effect a new baby may have on family life.

Description

In this activity, students consider what the world was like when they were born and what expectations and values parents and/or other caregivers had for them. This activity helps students to gather, organize, and analyze data from a variety of sources in the process of creating a class collage or poster.

Planning Ahead

Since students need to do outside research and interviewing to complete this activity, you might combine work on this exercise with the "Time Line to the Future" activity. Other suggestions for organizing the next few classes appear on page 35.

Procedure

Organizing the Class (20 minutes)
Read the introductory paragraph to your class and discuss the questions. You might suggest that students divide into three groups to do this assignment. However, students may want to suggest other styles of working. Encourage them to select the way of working on this and other assignments that they find most appealing and comfortable.

If students prefer to work in small groups, one group might search for newspapers, magazines, and other artifacts from the year when most class members were born. A second group might interview adults about their recollections of that year. A third group might interview members of their own family about their concerns for their children when they were born. Suggest some sources such as baby books, family memorabilia, the memories of their relatives, newspapers of the time, magazines, etc.

It is also important to be sensitive to the variety of family structures that exist today. Students who were raised in foster or adoptive homes, or in single-parent families, will bring a special and valuable perspective to this activity, if they choose to share their experiences.

Completing the Collage (2 ½ classes)
After the data have been assembled, students as a class should review all the information they have and then put together one collage/poster in "Our Beginnings." It is hoped that some information from each of the three general categories (or each of the three groups' work) will be included on the poster. Suggested discussion questions for summarizing this activity appear on page 7 of the student book. (Special Note: Save the collage / poster. Students will want to refer to it as they work through the exercise, "Beginning Again and Again.")

To schedule this activity, it may be helpful to set aside about 20 minutes of one class period during which students discuss the objectives of the activity. They might then divide into work groups and plan how they will collect and organize data for the next session. You might use the rest of this period to begin discussing the "Time Line" activity. You can then devote time to both activities during the next three or four days. Students may use part of each session to collect clippings for the collage and to relate the interesting features of the interviews they have been conducting, while also adding items to their own time lines.

When the "Our Beginnings" activity has been completed, you may wish to devote most of a class period to summarizing this activity. Then you can turn your attention in the next session to completing the time lines and dealing with the discussion questions.

Time Line to the Future (2 classes)

Materials

- Student book, pp. 10-11
- 3x5 index cards
- String or clothesline, or a long roll of paper to construct the time line

Purpose

- To think of parenting as one of the choices to be made during a lifetime; to consider when and under what circumstances to become parents.

Description

Students construct personal time lines that summarize major events from their pasts and project guesses about their futures. They think about when and under what circumstances they might become parents. Contemplating parenthood prompts students to discuss why, from a personal standpoint, certain times and circumstances may be more appropriate or better than other times for having a child. Students may also wish to talk about babies that just "happen" and the joys and problems that may accompany such events.

Planning Ahead

In the next activity, "Your Class Reunion," students are asked to talk with a person who graduated five or ten years ago from their high school about what's happened in their lives since graduation. You might know of another teacher in the school who is a graduate, or your students might have older brothers and sisters who went to the same school. Otherwise, you could ask the administrator/principal for the name of the tenth-year class reunion chairperson.

Procedure

The directions for this activity are included in a fairly detailed form in the student book on pp. 10-11. Students may choose the style of presenting their time lines that appeals most to them—hanging index cards on a clothesline or piece of string, unrolling a long piece of shelf paper or brown wrapping paper, etc.

At this time, the summary questions on page 11 of the student book can be discussed briefly. The time lines will be used again during the next week and discussed in a wider context. (Student responses to these questions should be recorded and saved for later use.)

Your Class Reunion (2-3 classes)

Materials

- Student book, p. 12
- Someone who graduated five or ten years ago from your high school

Purposes

- To think about the future.
- To practice skills of listening, interviewing, recording, and reporting.

Description

In this activity, students role play an interview with someone in their high

school class ten years in the future. This interview focuses on what has happened to the graduate in the intervening years. The exercise amplifies the "futures" theme introduced in the time line activity during the previous session.

Procedure

Organizing the class (15-20 minutes)
The class should first agree on a few questions that each interviewer will ask. You might write these questions on the board or on a large piece of construction paper so that everyone can refer to them.

To see how the questions work, you might select two students and have them interview each other in front of the class. The class can then comment on how the interview went and suggest new questions if necessary. The same questions will be used when students pair off and interview each other, and may also be used when interviewing the ten-year graduate in the next session.

Completing and writing up the interview (40 minutes)
It usually takes a full class for each pair of students to complete their initial interviews and compile their notes. (Note: Have students save their interview records for use in the "Beginning Again and Again" activity.)

Summarizing (15 minutes)
Students can share their interview records with other members of the class, and compare similarities and differences in their expectations and plans for the future. Because students were questioned by someone else, their responses may be different from those they gave during the "Time Line" activity. Many students tend to describe the kinds of things that appear in yearbooks—travel, jobs, marriages, education, and the like—as well as considering circumstances under which different people become parents.

Talking to a graduate (40 minutes)
Students enjoy talking to graduates of their high school, and finding out what's happened in their lives. You might be able to locate someone who still lives in the area and would be willing to come to class and talk about the events in his or her life since he or she graduated, including what some of the surprises were.

With your students, plan how to make the guest feel comfortable and how students will question their visitor. Plan to give the guest some time to describe some of the important events in his or her life since graduation.

At the end of the session, or at the beginning of the next session, allow time for a "debriefing" period. Discuss what the visitor said and encourage students to compare their own projections ten years into the future with the ten-year memories of someone older.

Ten New Families (3 classes)

Materials

- Student book, pp. 13-63
- Cassette tape recorder
- Newsprint and marking pens for recording small-group discussions
- Audio tapes

Purposes

- To understand that parenting significantly changes the life/lives of the parent(s) involved.
- To recognize that a significant number of adolescents become parents.
- To realize that parenting is a more satisfactory experience if a baby comes into the parents' lives when they are prepared (according to *their own* criteria) for its arrival.
- To begin to picture themselves in the role of parents.

Description

How and why do people become parents? How does becoming a parent affect different individuals? In these materials, family members discuss these questions from a variety of perspectives. All the interviews are real. They were excerpted from longer discussions with people in different regions of the country, who come from a variety of socioeconomic, religious, racial, and ethnic backgrounds. Due to technical difficulties with the original recording, the *Anthony* tape was rerecorded.

Some of the parents are adolescents, some are older; some are married and some are single parents; some are men and some are women. They all have unique perspectives on the impact a baby has had on their lives, and they describe the changes they perceive in the relationships among family members caused by the birth.

Planning Ahead

You might ask one or two students to read aloud or tape those case studies which are not already provided on audio tape. These tapes can be played during class or taken home by individual students for overnight listening.

Procedure

Organizing the class (15-20 minutes)
It is *not* intended that each student read every case study. Instead, students are asked initially to choose one case study that interests them, and to listen to, read, and discuss this selection in a small group with other students who are interested in the same case.

To aid students in selecting a case, brief descriptions of each family are given before every interview. You might want to list the names of the different parents on the blackboard (along with the page numbers on which the interviews appear in the student book) and then describe each family briefly before asking students to make their selections.

If your students have never analyzed case-study data before, you might choose one case and have the class work together on it before they begin working in smaller groups.

Special Note
A table of statistics about family structures and the occurrence of adolescent

parenthood appears on page 61 of the student book to remind students that significant numbers of them are, or will become, parents if present trends continue. You might take a few minutes during class to have students read the table and raise any questions or concerns they have. You might mention this table again at the end of the work on case materials to remind students that, although each person they read about is unique, their stories, combined with those of others in the United States today, add up to a very large number of people.

If students find these statistics especially interesting, they might want to share them with others. Brainstorm places where this information could be posted or printed. Examples may include the school newspaper, the local newspaper, or posters hung in the girls' and boys' gym, health classes, school cafeteria, or local health clinics. You might post a copy in your own classroom. Then, as students find more information, they can add it to the poster.

Reading and discussing the case studies (30-50 minutes)
Detailed instructions and summary questions to discuss in small groups are included on page 63 of the student book. Questions have also been included at the end of the interviews to help students focus on the particulars of each case.

After students read and discuss *one* case, you might ask them to read and comment on other cases to get an idea of the range of ways people feel that a baby has influenced their lives.

Summarizing the case study data (30-50 minutes)
After completing their small group work (or when you feel students need a change of pace), students should reasemble as a class and share their observations and discussions. (Case studies that were not selected for analysis can also be discussed by the class.) Specific suggestions for summarizing and comparing the case studies are given on page 63 of the student book.

Have the students re-examine their collage/poster, time lines, and class reunion data. Encourage them to reflect upon their responses to these previous activities. In light of the case-study data, would students add to or change their projections for the future? Have students explore this question further by writing a short story concerning their thoughts about personal relationships in the future, and their feelings about if and when a baby might be in their plans. (See page 63 of the student book, number 6, for specific instructions for this assignment.)

The First Nine Months of Life

In these brief materials, students are presented with some factual information: a doctor's notes on how a woman can know if she's pregnant, how she can get a pregnancy test, and a detailed month-by-month description of a pregnancy. This information is followed by activities that summarize all of the concepts that have been presented so far. Students are asked to consider again, in the light of this new information, what they will value when making such important decisions as whether to become a parent.

Nine Months to Grow In (1 class)

Materials

- One Doctor's Notes on Pregnancy, student book pp. 70 - 71
- Nine Months to Grow In, student book, pp. 72 - 87
- From Your Past to Your Future, student book, pp. 88 - 89

Purposes

- To gain information about pregnancy and normal fetal development.
- To understand the factors that can influence a baby's health from the moment of conception on.
- To understand that the first three months of pregnancy when all the baby's structures are being formed is the time when the fetus is most vulnerable to damage from its environment.

Description

Students want access to the facts they need about such subjects as pregnancy tests and the changes that occur during pregnancy. The first two pieces in this section have been included for this reason. The third is a summary section, intended to set the tone for the final activity, "Beginning Again and Again."

Procedure

One Doctor's Notes on Pregnancy (10 minutes)
Allow students time to read the pages of notes on pregnancy, and then ask for any questions. If there are questions that you cannot answer, you might wish to schedule an outside speaker—a biology teacher, for example, or a doctor—to discuss this piece and the material in "Nine Months to Grow In."

Nine Months to Grow In (20-30 minutes)
What happens to the parents and to the developing fetus during the nine months of pregnancy? This section describes the major events of fetal development. It focuses particularly on the first three months, when the fetus is especially vulnerable to birth defects and accidents. Comments by parents describe their awareness of what is happening, as well as their thoughts and feelings about these events.

Point out that different kinds of information are presented.

- *The drawing*: A scale rendition shows the approximate size of the fetus during the time period described on that page.
- *The heading*: This indicates the time period, and is followed by a descriptive quote from a woman at this stage of pregnancy.
- *The characteristics of the pregnancy*: The physical changes experienced by the mother, and the way she might be feeling physically and emotionally, are described.
- *Information about the fetus*: How it is changing size, which physical features and bodily functions are developing, and what activities are occurring within the uterus are described.

It might be helpful to allow students to follow one of these levels of information at a time through the pregnancy. For instance, students might like to read about how the mother feels at the same time they are discussing the case study of Mark and Ann Conroy. Ann is five months pregnant now, and students might like to discuss what parts of her pregnancy she has already experienced, how she is feeling now, and what she might yet experience before the birth of her baby. Later, when considering inheritance in *Families with Special-Needs Children*, students may wish to refer to this material. They will note that all the events of heredity occur at the time of fertilization, and that by the end of the second month all of the physical features have begun to form.

Beginning Again and Again (1 class)

Materials

- Student book, p. 89
- Time lines and poster/collage from previous activities
- Paper, paste, scissors, scrapbook binders for making a notebook

Purposes

- To make their own choices—choices that are based on knowledge of the probable consequences.
- To gain experience in problem solving and identifying alternatives.
- To review the data and information discussed so far and to consider if, and under what circumstances, they might become parents.
- To realize that parenting continues over a long period of time.
- To begin to picture themselves in the role of parents.

Description

This is a summary exercise for *Starting A Healthy Family: Choosing Parenthood*. Students have an opportunity to reconsider their thoughts and feelings from previous activities and materials, and to think again about their own futures and about the role a baby might have in their lives.

Sample Lesson Plan

"When You Were Born" and "Time Line" (5 classes)

Day One	
Organizing the class for the "When You Were Born" activity.	20 minutes
Brainstorming sources of data and discussing how to collect information.	15 minutes
Introduction of "Time Line" activity.	5-10 minutes
Day Two	
Class discussions of data and information collected for "When You Were Born" activity.	20 minutes
Introduction of "Time Line" activity (if you haven't done so previously); students begin writing down past events and future plans for their "Time Lines".	20 minutes
Day Three	
Group discussion of "Our Beginnings" collage.	40 minutes
Day Four	
Summary discussion of "Our Beginnings" collage (if not completed previously).	10-15 minutes
Work on "Time Lines".	25-30 minutes
Day Five	
Completion of Time Lines and summary of work.	40 minutes

Sample Lesson Plan

Your Class Reunion (2-3 classes)

Day One	
Organizing the class to interview each other.	15-20 minutes
Students work in pairs and interview one another.	20 minutes
Day Two	
Students write up their data.	15-20 minutes
Discussion of similarities and differences in plans for the future.	10-15 minutes
Planning for tomorrow's visit by a ten-year graduate of the high school.	5-10 minutes
Day Three	
Visit by a graduate to the class.	1 class
Day Four	
Debriefing	10 minutes

Sample Lesson Plan

Ten New Families (3 classes)

Day One	
Introduce the case studies.	10 minutes
Students select a case to read and form small groups; a recorder is selected in each group to keep notes on discussions.	10 minutes
Reading and discussion of one case.	20 minutes
Day Two	
Students continue small group work, discussing 2-4 other cases.	30 minutes
or	
Class listens to and discusses tapes of a case study.	20-30 minutes
Small groups summarize their discussions for use in class tomorrow.	10 minutes
Review statistics on adolescent pregnancy.	5 minutes
Day Three	
Class compares similarities and differences among case studies.	20 minutes
Review students' poster/collage, time lines, and class reunion data.	10 minutes
Students begin their short stories about their futures .	10 minutes
Homework: completion of short stories.	

Families with Special-Needs Children

Families with Special-Needs Children focuses on the impact of children with birth defects on families, and the ways various families cope with the needs of these children. The materials have been designed to enable students to shift from the considerations all parents have when deciding to have a baby to an examination of parents' reactions when the baby they have waited for with such hope has severe problems.

Learning Objectives

- To explore the impact a child with special needs has on a family.
- To consider how families cope with the needs of their special children.
- To consider how the community and individuals can help these families.
- To consider genetic causes of birth defects.

Possible Class Sequence (8 classes)

Class 1	Jenny MacLean
Class 2	Talking to Dr. Neil Macintyre Mirror Image Activity
Class 3-4	Two Families Cope Talking with Dr. Robert Cooke
Class 5	Geri Gable
Class 6	Bill and Margot Kaldma
Class 7	Birth Defects: Why do They Happen?
Class 8	Inheritance: The Biological Connection

Planning Ahead

Audio-visual Equipment

Several case studies in this and the next book require the use of audio-visual equipment: Neil and Donna Hobson and Bill and Margot Kaldma are on tape cassettes and require a tape recorder. A filmstrip is provided with the Geri Gable case study so you will require a filmstrip projector as well as a tape recorder.

Outside Speakers

The case studies in this book are followed by material on birth defects and

inheritance. You might invite a doctor, science teacher, genetics specialist, or March of Dimes professional to class to discuss this material with the students.

If you will be going on to *Families and Futures: Helping Self and Others* after completing this book, you might want to start lining up the following speakers now. None of these speakers is required, but students might find them interesting and helpful.

- A special-needs teacher or counselor from your school to discuss Stephen Slater's material, in "Students with Special Needs in Regular Classrooms."
- Resource people for the section "Fostering Healthy Growth"
  —an obstetrician (on prenatal care)
  —a biology teacher (on nutrition)
  —a social studies teacher (on family income)
  —a chemistry or biology teacher (on medication and environmental hazards)

Establishing a relationship with a key referral person who specializes in special-needs work in your community will facilitate student activities with the "Yellow Pages" projects in *Families and Futures: Helping Self and Others*.

Yellow Pages projects

The Yellow Pages projects are described at the end of this teacher's guide. They ask students to examine community resources for people with special needs and compile their findings in a notebook or card file. In *Families and Futures: Helping Self and Others*, ideas for these projects are found in "Ellen's Story," "Service Projects," and "Fostering Healthy Growth."

When to Read
Families with Special-Needs Children and *Families and Futures: Helping Self and Others* contain a great deal of data and involve a lot of reading for students. If you are using the two books together, we offer two suggestions for covering this reading, and suggest that you choose the one that is most comfortable.

- Divide the "Helping Yourself" section of *Families and Futures: Helping Self and Others* into sections and have small groups read, discuss, and report to the class on each section. Spend one class at the end of *Families with Special-Needs Children* on this activity.
- Assign "Helping Yourself" for reading at home while students do *Families with Special-Needs Children* and the first part of *Families and Futures: Helping Self and Others* in class.

These suggestions are discussed in greater detail in this guide.

Assigning and Doing the Yellow Pages Projects
There are also two ways these projects can be done.

- If *Families and Futures: Helping Self and Others* is divided into sections and read in class by small groups, each group can report on the project suggestions in their section. Between work on *Families with Special-Needs Children* and "Helping Others" (the first part of *Families and Futures: Helping Self and Others*), students can select project topics they would like to work on. Class time can then be set aside at intervals during "Helping Others" to work on projects.

- If "Helping Yourself" is read at home, you might spend a week at the end of the course discussing the material and doing the projects.

Five Families

Jenny MacLean (1 class)

Materials

- Student book, pp. 3-5

Purpose

- To show how parents respond when they first learn that their newborn baby has a birth defect.

Description

This transcript tells the story of two parents' experience when they learn that their infant son has Down's Syndrome. It focuses primarily on each parent's initial reaction, their own parents' reactions, and the pediatrician's prognosis for the future.

Procedure

Since there is no tape for this piece, you might ask a student to read it ahead of time and prepare to read it aloud in class. To help students empathize with Jenny or her husband, you might ask students to imagine and describe how they would feel in this situation. Students might also look ahead to the piece by Dr. Macintyre on page 6 of the student book and compare Jenny's reaction with this doctor's description of the initial reactions of most parents.

While other case studies in this book discuss birth defects with unknown causes, Down's Syndrome has a known genetic cause. Recalling what they learned earlier about normal prenatal development, students might now read the information on genes and chromosomes on pages 33-41 of the student book and on Down's Syndrome in the glossary to answer some of their questions about genetic accidents.

Questions

The discussion questions can be answered in a large or small-group setting. The questions might be divided among small groups, who then share their thoughts with the class. The two activities can be done at home by individual students or done in class in two additional small groups. Whether individual students or small groups write letters or tape phone calls as friends of Jenny, some of these could be read or played in class. Listeners can then comment on whether they would find these helpful if they were Jenny. If several students write from the point of view of Jenny's husband, compare these versions and discuss reasons for the similarities and differences.

Talking to Dr. Neil Macintyre (1 ½ classes)

Materials

- Student booklet, pp. 6 - 8
- Mirror image activity, page 9
- Tips for listening, page 9

Purposes

- To describe a range of reactions most parents experience when coping with having a child with special needs.
- To suggest ways to support such parents.

Description

Are there reactions that most parents of children with birth defects experience? What are some of the ways that these parents can be helped? These questions are explored in depth in the conversation with Dr. Neil Macintyre, a genetics counselor from Case Western Reserve Medical School.

Procedure

Encouraging students to think of specific examples of Dr. Macintyre's statements can help their understanding. For example, why might the grandparents of a child with birth defects feel threatened? What are some situations that might make siblings or friends uncomfortable? For this discussion, you could copy these two questions on the board, or focus on the questions at the end of the interview. You could also assign some questions to be written at home.

In discussing Dr. Macintyre's interview, students might need help in dealing with some of the emotions Dr. Macintyre feels parents experience initially, such as the wish that their child would die. These are legitimate feelings, but people are too often taught never to express any anger toward their unfortunate offspring or any resentment about how much more difficult it is to care for, plan for, and communicate with this child.

Mirror Image Activity (1 ½ classes)

Materials

- Student book, p. 9
- Tape recorder and cassettes
- Sample forms duplicated from this guide, pp. 43-44

Purpose

- To develop and practice listening skills so that students might listen and respond to individuals with special needs, and to their parents, in ways that are helpful to these people. This activity can also help students develop good, sensitive listening skills in any situation.

Prepare Ahead

If possible, collect a tape recorder for each pair of students in the class. Some students may be able to bring tape recorders from home. To prepare for this activity, students might write notes at home on the incident they want to describe to their partner. The suggestions focus on listening to people with problems, but not all students may want to talk about particularly difficult encounters. To help them choose an incident, you might suggest possible situations with a parent, a brother or sister, a friend, a neighbor, or a teacher. Help them fill in the details of the incident by reminding them to include when and where it happened, who was involved, what it was about, and what was said. In addition, encourage them to include how the incident made them feel, why they did what they did, and what questions they have about it. (You might copy the form on page 43, which provides space next to each of these categories for students to write in their own details.)

Procedure

With these preparatory notes, have students pair off in class and do the "Mirror Image" activity described in the student book on page 9. Reversing roles (i.e., having the partner retell the same incident) serves two purposes:

- How well did your partner really listen? Did he or she really understand how you felt?
- When you took the role of listener, did you feel you fully understood how the teller really felt? Considering this, how did you respond? Why?

When students listen to their tape recordings, they can discuss these questions as well as the questions in their book about what makes a person a good listener.

Instead of tape recording, you could ask some students to observe the partners (one or two observers for each partner), keeping the discussion questions in mind. (If you do this, you could make out a form like the one on page 44 as a checklist for observers.) Observers can then contribute to the partners' discussion of good listening skills.

To close this discussion, partners might share their thoughts about the activity with the class. Then the class as a whole might read and comment on the tips from teenage "hotline" counselors.

Notes for Describing Incident in Mirror Image Activity

Name.....

Who was involved:

_____

_____

When it happened:

_____

_____

Where:

_____

_____

What it was about:

_____

_____

Who said what:

_____

_____

How it made me feel (during incident):

_____

_____

Why I did or said what I did (later):

_____

_____

How I feel about it now:

_____

_____

Mirror Image Activity Observation Form

Name.....

How the incident was first told:

Examples that show teller may or may not understand how first student felt in the situation:

How does the teller retell the incident:

How does the listener respond (note responses and what was said before responses):

Examples that show the teller did or did not listen well:

Why do you think listener made these responses:

Neil and Donna Hobson
The O'Mally Family (2-3 classes)

Materials

- Neil and Donna Hobson transcript, student book, pp. 10-13
- Audio tape and tape recorder
- The O'Mally Family transcript, student book, pp. 14-17

Purpose

- To recognize qualities in two families that helped them cope with having more than one child with special needs.

Neil and Donna Hobson

Introduction
The Hobson audio tape is an interview with the parents of a seven-year-old son who is normal, a six-year-old named Jeffrey with cerebral palsy, and a six-month-old baby named Joshua with brain damage. While Neil and Donna have different approaches to their family problems and different methods of coping with them, their strength as partners lies in their ability to articulate their feelings to one another.

Prepare Ahead
Obtain a tape recorder and cassette of this interview. Read "Range of Retardation" in the student book (p. 29) so you can refer students' questions to the appropriate reading during class discussion.

Tips for Listening to Audio Tapes
You might begin by telling students that the tapes they will listen to in this module are real discussions, edited only for brevity. Explain to students that the parents heard on the tapes are not actors. The incidents and comments were not chosen as models of good or bad practice, but to illustrate some real situations.

Before using a tape at a session, you might listen to it yourself. Have the transcript in hand, so you can take down any notes that might help with the class discussion.

Since the listening skills of individuals vary, you may want to use the transcripts to help students recall what was said on the tape.

When planning to listen to audio tapes you might:

- Use the transcript to formulate discussion questions about the taped experience. It is a good idea in phrasing the questions to use the same words as the speaker.
- Group students around the cassette player. (Sound distortion occurs when the volume is raised to the highest level.)
- Suggest that students follow the transcript in their books while listening to the tape. This may help them gain a better focus on what they are hearing.

- During discussion or activities following the tape, you might clarify or recall information for participants by reading directly from the transcript.

Since these tapes cannot be erased accidentally, you might loan one to a student who wishes to hear it again or perhaps share it with other students and family outside of class.

Procedure

A procedure for listening to the Hobson tape might be to introduce the family briefly, listen to the tape while following transcripts, allow open time for initial reactions, and then divide the class into small groups for discussion of specific issues. Each group can refer to the transcript for evidence related to their 17 questions. When reporting to the group, they can use the transcript to quote relevant phrases.

The questions on page 17 of the student book deal with the Hobson and O'Mally families together. The following questions might be used to discuss just the Hobsons; the class might divide into three groups, each focusing on one set of questions.

- *Impact on the family*: How has this family been affected by having children with birth defects? (Consider their initial reactions, as well as later changes in their lives.) What was the effect on the relationship between husband and wife? What was the effect on their eldest son?
- *How the family copes*: What personal strengths and beliefs have helped these parents to cope with their children's special needs?

  The interview with Dr. Cooke that follows the Hobson and O'Mally transcripts centers around his belief that parents cope best by concentrating on one day at a time. It parallels Neil Hobson's philosophy that his role is to make each day as fulfilling and happy as possible for each child. The small group discussing this question might read and discuss the Cooke excerpt, and report on it to the class.
- *Responding to a range of special needs*: The Hobson family represents the way one set of parents responded to two very different kinds of birth defects. What similarities and differences are there in the ways the Hobsons respond to Jeffrey and Joshua? (Consider how the children's ages and the severity of their birth defects might affect their parents' responses.)

The group could fill out a sheet of paper like this:

Similar Attitudes and Ways of Treating Jeff and Josh	Differences
	Jeff (6 years)
	Josh (6 months)

Students often think that families who care for their children with special needs at home are successful, while they view families who institutionalize their children as failures. It is possible, however, that a family might make two different decisions based on the needs and abilities of two different children. (The O'Mally Family case illustrates this point.) When this small group reports to class, you can discuss the idea that what a family does may depend on the child as well as on the family's ability to cope.

The O'Mally Family

Introduction
The interview with Peggy O'Mally is interesting in several respects. It offers another case study of how birth defects can affect a family—this time, from a sister's point of view. Students should easily be able to identify with Peggy. Her story offers a vivid picture of life with a girl who has a serious genetic defect. It may surprise students to learn how much some children with Down's Syndrome are able to grow and develop. This case study also shows parents who did not agree what to do about their special-needs children and made two different decisions for two children. While these parents disagreed, they openly acknowledged and accepted their differences without attaching blame to anyone's feelings or actions.

Plan Ahead
Ask one or two students to prepare to read this transcript aloud.

Procedure

This transcript can be divided and read aloud by students in class. Students' questions about Down's Syndrome can be referred to the glossary and to the section on inheritance (pp. 33-41). Several questions focusing on the O'Mally family can then be discussed in small groups or by the whole class.

Effect on Siblings
Peggy says she enjoyed having Mary at home. Look through the transcript for some of her reasons. She also said she had a hard time dealing with it. What are some of the things that she said were, or still are, difficult for her? How do you think you would feel if you were Peggy? Peggy also says that Mary is "very much a member of the family." Look for evidence of this in the transcript.

Effect on Parents
Peggy describes her parents' conflicts over whether to have Johnny and Mary at home. What does she say about each parent's feelings and reasons. How has having two children with birth defects affected their lives? What strengths have they drawn on in caring for their children? What would you want if you were the father or mother?

Individuality of Mary
As Peggy says, "children with Down's Syndrome are not all alike." What are some things Mary can and cannot do? In what ways does she seem like any other teenager?

Questions

While the questions on page 17 of the student book invite comparison of how two different families cope with similar problems, the intent is not for students to judge any family as coping better or worse than another family. You should encourage students to view each family as unique, with unique individuals in unique situations. The students' task is to learn what attitudes and behaviors help or don't help in each situation, and how what they learn might apply to their own situation, to friends or neighbors they might know, or to people in their community.

Procedure

In looking at factors in both situations that enable family members to cope, students might make a list for each family. (Two groups could each do one list and then compare their lists.) Some factors students might list for the Hobsons include the father's determination and religious faith, his ability to make the most of each day, his acceptance of his children as they are, both parents' willingness not to hide their children, and their ability to share their feelings and to support, rather than blame, one another. For the O'Mallys, students could look at some of the personal qualities of the narrator: her acceptance of her sister and of her parents' decisions, and her ability to keep in perspective both the difficulties and rewards of having siblings with special needs, for example. They could consider what strengths the parents may have that fostered these qualities.

When considering whether particular family members needed or might need assistance, the class might again divide in half. Students should be cautioned against judging one individual, such as Mr. O'Mally, as wrong for not accepting his first son or for treating his Down's Syndrome daughter differently at home and in public. (Note that his family does not blame him.) Encourage students to look instead at how he might be helped to become more accepting of his children. You might ask students to consider the following questions:

- How can neighbors, friends, storekeepers, gas station attendants, etc., act in ways that tell parents they and their children are accepted and liked?
- How can you do this for people in your neighborhood? (Tell students about the case studies they will read about later; the cases of Bill and Margot Kaldma in this book and Mark Motta in *Families and Futures: Helping Self and Others* look specifically at how communities and neighbors can support parents of special-needs children.)

When students reread the Hobson transcript from Donna's point of view (see "To Think About," p. 17 of the student book) they may note that Donna describes herself as "angry" and a "worrier," and that she seems less accepting than Neil of Joshua's future. Students can focus on the support Donna gets from sharing her feelings with Neil, and from her neighbors' acceptance of Joshua. What else might help Donna?

Dr. Robert Cooke: One Day at a Time (20 min.)

Material

- Student book, p. 18

Purpose

- To present the point of view that taking each day as it comes and accepting children as they are is the best way for parents to respond to children with special needs.

Introduction
This portion of writing by Dr. Cooke, a pediatrician and a specialist who works with families of children with special needs, offers another professional's perspective on how families can respond to and cope with children with birth defects.

Procedure

The passage can be read and discussed in class after the Hobson and O'Mally case studies; or it can be assigned for reading at home, together with questions to be answered and turned in to you. In addition, students might spend time comparing the advice offered by Drs. Macintyre and Cooke. They might also look for examples of what the doctors suggest in all of the case studies they read in this book. How has each family in the case studies coped with having a child with special needs? Have they done things that either doctor suggests is helpful? If so, what? And what other specific suggestions do these doctors make that you think could help each of these families?

Geri Gable (1 class)

Materials

- Geri Gable transcript, student book, pp. 20-22
- Filmstrip projector
- Tape recorder and cassette

Purpose

- To consider the rewards and difficulties one person experiences in parenting her special-needs child, and to consider how some childrearing difficulties are shared by all parents, not just those of children with special needs.

Introduction
Geri, the mother of a 19-year-old mentally retarded daughter, did not learn that her daughter was retarded until Laurie was 16 months old. She has raised Laurie at home. On the tape, Geri describes this experience over the past 19 years. We have chosen to present a filmstrip to accompany this interview so that students will be able to see not only a retarded child but also a retarded adolescent/adult.

Prepare Ahead
Assemble filmstrip projector, tape recorder, and "Geri" filmstrip and cassette. Read "Range of Retardation" to refer student questions to the appropriate text, and read the material in this guide on Yellow Pages (p. 72). Decide when to assign the final question/project on facilities for retarded adults.

Procedure

Read the introductory material about Geri and then show the filmstrip. Students should not try to follow their transcripts while viewing the filmstrip, but they can refer to them during later discussions.

(Note: The first three frames on the filmstrip are title slides. Start the audio tape at the fourth frame on the filmstrip—baby picture of Laurie. Tone signals are included on the audio tape to indicate when the filmstrip frame should be changed.)

Initial discussion
This six-minute filmstrip is extremely moving; many students may have difficulty responding to questions immediately afterward. To help, you might plan four or five minutes of general comments before focusing on the specific questions and activities in the student book.

You might ask students about their initial reactions to the filmstrip and how it makes them feel. You might also begin with some of your personal reactions before asking for student comments. For example, one teacher was struck by the contrast between Geri's emphasis in the narration on problems, and the warmth and closeness conveyed by the pictures.

For a while, students may want to focus on the pictures themselves. You could ask a general question for discussion such as: What is your reaction to the photos? If appropriate, you could further include more specific questions. Can you tell Laurie is retarded? Does she look like someone you'd like to know? Do any of the photos remind you of scenes from your own childhood? How might Laurie's birth defect make these scenes different from those you remember? What can you learn from the photos about Laurie's relationship with Geri, her mother? What evidence can you find in the photos that Laurie is "more a part of [Geri's] life than [she] can explain to anybody"?

Questions

The first three questions for discussion can be done in three small groups and then shared with the whole class. A fourth group might begin the research project on community facilities for retarded adults.

In comparing Geri with the O'Mallys and Hobsons, students should again be cautioned not to judge any parents as coping better or worse than others. In one small group, students might consider how they could become comfortable babysitting for a retarded child. For example, what questions would they ask the parents? What can the child do or not do? What special help does the child need? What difficulties might arise, and how should they respond to them? What does the child like to do? Who could they call if they needed assistance?

Are there any friends or relatives who might have had experience caring for this child or another retarded child? They might consider spending time together with the parents and the child before assuming responsibility alone.

After considering these questions, students could then role-play a telephone conversation in which the parent of a retarded child calls and asks them to babysit. The group could present this role play when reporting to the class. Some students may still think they would be uncomfortable in this situation, and may be able to explain why. How might these students gain direct experience with retarded people? For example, could they work in a residential or day care program? You might hold the last question until the whole class begins work on the "Yellow Pages" projects, or you can assign a small group to begin searching out resources for retarded adults in their own communities. Students in this group could get together and divide responsibilities. For example, one student could call community mental health agencies, one could call a special education teacher, and one might collate the information collected and enter it in the Yellow Pages.

When students talk to various agencies, they should take notes on what resources the agencies offer, ask for literature to be sent to class, and find out if students can visit and observe. What help do these facilities offer retarded adults and their families? Do students find this support adequate? Are there enough facilities for all of the families who need them in your community? Note that the case of Mark Motta in *Families and Futures: Helping Self and Others* is an example of how a community can provide for a handicapped adult.

In addition, students might recall or reread Dr. Macintyre's description of stages in parents' reactions to having a child with special needs. Stages they might then note in Geri's relationship with Laurie could be:

- Innocence of any problem
- "Hysteria" on first hearing diagnosis
- Suppression—"it'll be all gone"
- Turning to others—grandparents, father, sitters, doctors, social workers
- Despair—"but she's 19," "I would have readily accepted Laurie being placed in a home," "I was at my wit's end"
- Acceptance, comfort—"...more a part of my life than I can explain to anyone"

As in the above list, students might quote signs of change in Geri's attitude and try to give each change a descriptive name. An understanding of these stages might help students understand the experience of someone they know who is faced with a special difficulty.

Range of Retardation

Many students find it helpful to use the glossary to name and discuss specific birth defects, focusing on what individuals with these defects and with different degrees of impairment can and cannot do (both physically and mentally). For

this discussion you might invite the school nurse/doctor or the special education teacher to class.

The student book section on Range of Retardation (p. 29) can help students understand the causes and range of effects of this birth defect. Mentally retarded individuals can be as different from each other as your students are, and what Laurie can or cannot do is not necessarily representative of all retarded youngsters. The major point to stress to students is that retarded children or adults need to be seen as individuals.

Bill and Margot Kaldma (1 class)

Materials

- Bill and Margot Kaldma transcript, student book, pp. 23 - 27
- Audio cassette and tape recorder

Purpose

- To reconsider how parents react and cope with having a child with special needs, and to consider supports offered by family and community members.

Introduction
In this tape, Bill and Margot talk about their own reactions, and the reactions of their family and friends, to the birth of their blind son. They also discuss the problems they have had to deal with as parents of a special-needs child, as well as the help different members of the community have provided.

Plan Ahead
Assemble tape recorder and cassette.

Procedure

Introduce Bill and Margot's family. Then play the audio tape. Have students follow on their transcripts.

Questions

To discuss questions 1, 2, and 3 in the student book, you might divide the class into three small groups, each working on one question. Each group could then report its ideas on (1) guilt, (2) marriage, and (3) grandparents to the whole class. As part of this discussion, you might reread the sections of Dr. Macintyre's interview dealing with marital strain, guilt, and grandparents.

Question 4 focuses attention on informal resources (the grocer, the bus driver) that a community can offer to a family with special needs. In considering how untrained people in the community can be supportive of families and children with special needs, students are really considering what they can do for people in their community. The whole class could discuss the questions and together brainstorm a list of supports to families of special-needs children. To help students think of different resources, have them think about the parents in the other case studies. What helped them? What other help did they need?

Students might consider how a birth defect can affect every aspect of a child's life and development and has implications for child care that might not be readily apparent. Students might think about other defects (e.g., deafness, immobility of a limb) and try to imagine how this would affect a child's life. For example, they could list things they do in a typical day and consider how this would change with a particular birth defect. Small groups of students could work on different defects and report their thoughts to the class, or students could write this assignment at home.

Did You Know? (1 class)

Materials

- Student book, pp. 28 - 29

Purpose

- To answer student questions about case studies dealing with mental retardation

Introduction

The material in "Did You Know?" and "Range of Retardation" answers questions many students have asked about what mental retardation is, how widespread it is, how severe or mild it can be, what causes or prevents it, and what retarded people can and/or cannot do. It should be read with the case studies or at home.

Prepare Ahead

You should read this material yourself before discussing Neil and Donna Hobson, the O'Mally family, or Geri Gable, to be prepared for students' questions when they come up.

Procedure

Ideally, you can use this material with students when discussing the case studies. When questions arise, you and the students can turn to the appropriate place in the student book for answers. If students do not raise questions after reading the transcripts or after discussing issues in small groups, then this material might be assigned for at home reading. Students may have questions about how mental retardation is diagnosed, or once diagnosed, how the severity is classified. You should note that while the criterion that retarded persons do not catch up with others of their age is a useful definition, it covers a very broad range of abilities and does not help parents predict what their child's needs will be in the future. Current testing procedures are anything but foolproof and there is still much to learn in this area. Further discussion might include consideration of what problems there might be in devising an accurate test for evaluating retardation and how test results might be helpful or harmful to parents.

Birth Defects: Why do they Happen? (1 class)

Materials

- Student book, pp. 30 - 31

Purpose

- To answer common student questions about birth defects and to introduce the notion of the interaction between genetics and the environment in causing birth defects.

Description

This class and the one that follows on inheritance conclude the book, *Families with Special-Needs Children*. Some of the reading is quite technical—the subject of genetics is complex; some students may not understand right away how recessive and dominant genes work, for example—but the material is generally fascinating. If some students have already studied genetics in science, they may be helpful in explaining certain concepts and processes. You might want to invite a specialist to class to answer students' questions, which may go beyond the material presented in this book.

This section is in question-and-answer format and provides answers to some of the more common questions students ask about the nature, incidence, and diagnosis of birth defects. It is not intended that these materials be an in-depth exploration of all the known facts about birth defects, but rather an overview of some of the more general concerns students have voiced.

Procedure

Have students read this section along with the material on inheritance (pp. 33 - 41) and the glossary at home or in class to prepare for discussion. You may want to assign the reading over two nights, with one class discussion in between.

Inheritance: The Biological Connection (1 class)

Materials

- Student book, pp. 33-41
- The glossary

Purpose

- To examine some genetic causes of birth defects

Description

This section describes various ways that birth defects occur.

Plan Ahead

Arrange for a specialist on heredity to visit the class and help explain this material. Assign the "Family Medical Record" activity in this guide (p.88).

Procedure

This reading can be done at home or in class. In either case, have students write down questions for discussion in class.

You may want to review the material in *Starting A Healthy Family: Choosing Parenthood* on normal genetic processes before beginning this section. The glossary will be a useful resource during this reading. It contains additional information about some of the medical terms used in the student book such as Down's Syndrome, brain damage, genes, etc. Students can refer to the glossary for descriptions of birth defects that are listed but not explained in this section. You might invite a specialist, such as a March of Dimes representative or an obstetrician, to come into class and talk more about hereditary birth defects. You can give the specialist a copy of the student reading before he or she comes to class.

Some student questions on this material may grow out of experiences in their own families or in families they know. If there have been birth defects in their own families, students may want to know about the chances of their own children having similar problems, or they may want to know which diseases in their families are hereditary. Students can use the background reading in this guide, "The Family Medical Record: A Step Toward Better Health," to help answer some of these questions. If you want to duplicate the form in the article, students might fill it out at home with help from their families.

The histories need not be shared in class if students find this subject difficult to discuss. On the other hand, students may have fears about their family histories, and may appreciate a chance to ask questions. If you invite someone with knowledge of genetics to help explain inheritance, they could ask their questions then. If you feel students will be uncomfortable asking questions in front of the class, you might have them write their questions down ahead of time and hand them in to you. (We suggest you extend this chance of privacy in an offhand manner, so students don't get the idea that the subject is not fit for open discussion. For example, you might ask to have the questions written down for the convenience of the speaker, and also give students a chance to ask questions out loud if they want to.)

Sample Lesson Plan

Jenny MacLean (1 class)

Read the introduction to the case silently or aloud.

Introduce the transcript and discuss the idea of developing empathy with the parents.	10 minutes
Read transcript aloud.	5 minutes
Divide in small groups: Five groups for discussion questions Two groups for activities.	15 minutes
Groups report to class.	10 minutes

Sample Lesson Plan

"Dr. Macintyre," and "Mirror Image" activity (1-2 classes)

Day One

Summarize parts of interview already discussed.	2 minutes
Divide into small groups to read and discuss parts of interview. Each group can discuss their thoughts about the questions at the end and then write out their ideas as homework.	15 minutes
Briefly share ideas about the listener's role with the whole class (see p.42 of this guide).	3 minutes
Divide the class into pairs. (Include one or two observers for each pair if there are not enough tape recorders. Give observers a form like the one on page 44.) When the cycle of telling an incident, reversing roles, and discussing the questions about listening is completed, the cycle should be repeated for the second partner.	20 minutes
If observers are used, the first pair of partners should be observers when the first observers take the roles of listener and teller. This activity could be carried over to a second class if it becomes too long.	0-20 minutes

Day Two

Pairs and observers continue and complete the activity.	5 minutes
Partners share thoughts with the whole class.	10 minutes
In pairs, discuss an actual person who listens well or, individually, write about such a person.	5 minutes

Sample Lesson Plan

Geri (1 class)

Introduce the filmstrip with background information about Geri from the beginning of the student transcript. Tell the class that the filmstrip can help them visualize a retarded girl as a child and as an adolescent/adult. Show the filmstrip.	6 minutes
Open the discussion for reactions to narrative and visuals. Refer students to "Range of Retardation."	10 minutes
Divide into small groups to discuss the questions.	15 minutes
Small groups report to class.	15 minutes

Families and Futures: Helping Self and Others

Helping Others: What Can We Do to Help?

In the third student book the focus shifts from the impact of a child with birth defects on the family to the perspective and special needs of teenagers with birth defects. Students also consider how these needs can be met by individuals and institutions in the community.

Learning Objectives

- To consider the special needs of adolescents with birth defects.
- To consider how informal contacts with members of the community, neighbors, and school-age peers, affect adolescents with special needs.
- To consider a range of society's attempts to meet these special needs.
- To consider the special problems of adolescent parents of children with special needs, and the resources available to them.
- To consider how to help people in the community who have special needs.

Possible Class Sequence (6 classes)

Class 1	Stephen Slater (with Dr. Cooke)
Classes 2-3	Mark Motta Notes from a Teacher's Aide
Classes 4-6	Ellen's Story

Stephen Slater (1 class)

Materials

- Student book, pp. 4 - 6

Purpose

- To consider the special needs faced by a retarded adolescent attending a public school and to consider how the school and your own students might help such a special-needs student.

Description

Stephen Slater is the first case study in which students will find an adolescent with a birth defect who has been "mainstreamed" in a regular public high

school. Mainstreaming is the term used to describe the placement of special-needs students in public schools, rather than placing them in special schools. Most likely your school system has acquired special-needs teachers and counselors as a result of recently passed laws, and the students affected by these laws may have been placed in your classes. Therefore, a major focus in discussing this case study should be on how schools, and particularly your own students, can respond to such students.

Planning Ahead

If there are special-needs students in your own class, you might read these materials ahead of time with these students and let them choose the role they want to take in class discussion. Do they want to share their own experiences? Do they want to discuss only Stephen, without referring to their own school? Are they uncomfortable about having the materials discussed at all? If you judge this to be true (and you may know that the student would be uncomfortable even answering these questions), you can assign the materials for reading at home.

If your school has a special counselor or teacher for students with special needs, consider giving them the material to read and inviting them to visit your class.

Procedure

This case can be read along with the introduction, "Students with Special Needs in Regular Classrooms," (page 3) and with the counselor's notes (page 6) during the same class period. The case study itself should be read aloud. In addition, students should read the Dr. Cooke interview, giving hints on how to act with special-needs persons (page 22).

Questions

The questions following this reading fall into three general categories and can easily be discussed in three small groups: one group might discuss Stephen and friends, while another discusses integration into the public school, and a third discusses the counselor's notes. Each group should refer to the transcripts and quote from the case study or the counselor to support their ideas. The group discussing friends should refer to the interview with Dr. Cooke and consider how his insights might apply to Stephen's case. The social worker's notes in the background readings at the back of this guide also contain ideas about being with people with special needs. (You might want to read this aloud to the class, or duplicate it for reference as needed.)

The Activity

While this activity suggests action students can take to help special-needs students in their school, several issues should first be discussed in class. Students might begin by focusing on the following questions:

- What has Stephen taught you about the problems faced by students with special needs in your own school?

- How do you think their problems are similar to or different from your own?
- What has your discussion about being a friend of Stephen taught you about the problems of special-needs students?

Students might then consider how they and the school itself can help such students:

- If Stephen were in your school what could you do to alleviate some of the problems he describes?
- How could you make it easier for a person with special needs coming to your school for the first time?
- What should your school do to become more responsive to special-needs students.

If your school has special counselors or teachers for special-needs students, talk to them. (Save your notes for the Yellow Pages resource file). What services do they offer? How do special-needs students benefit from the school's services? What problems do they see for these students in your particular school? (If such a teacher visits the class, have him or her read the Slater case study first.)

Following these preliminary discussions, students can list specific suggestions for helping special-needs students in their school and plan to discuss them with the student council, school administration, or guidance office.

Mark Motta (2 classes)

Materials

- Poster
- Student book, pp. 8 - 21

Purposes

- To consider the support an adolescent with special needs requires from the community, and to consider what makes it easy or difficult to give and receive such support.

Description

The pieces about Mark Motta reveal how much support friends and neighbors can offer a family with a special-needs child. They vividly illustrate some of the problems and rewards encountered when a person with special needs joins in everyday community activities. Included is a description of some community facilities set up especially for children and adolescents with special needs. Mark (a 20-year-old with cerebral palsy and possible mental retardation) is portrayed as a unique individual with normal as well as special needs and abilities.

Planning Ahead

Assign students to bring in pictures and papers representing their involvement with their community (optional, see supplementary activity, p. 62). In addition, have certain students prepare to read the case studies aloud.

Procedure

The Poster

The poster shows photographs and memorabilia of Mark Motta at different ages with his family, with his neighbors, and in relation to the larger community. Students could choose three pictures and describe in writing what the photographs or documents tell them about Mark:

- What is he like?
- What are his interests?
- What does he do?
- What is his relationship with those around him?
- What people and agencies in the community have been involved with him?
- What is his relationship with community agencies?
- How is he seen by others?

In writing, students should cite the evidence in the pictures that supports their views. Students who have written about one or two of the same pictures could get together and compare ideas.

As a class, the students could then examine the poster, looking for patterns in Mark's life:

- What things seem the same as Mark grows older?
- What has changed?

Poster Activity

The following activity could follow the discussion of Mark's poster or be used as an introduction to working with the interview with Mark Motta himself. Students could assemble a poster of their own, individually or collectively, which would focus on items that represent their own involvement with the community. To help students start collecting, the class can brainstorm a list of community groups, services, and events that deal with children and adolescents: for example, neighbors, youth groups, clubs and organizations, health services, special events like concerts or parades, musuems, and libraries. Students can then collect anything that represents their contacts with the community, such as photographs, membership cards, graduation certificates, health forms, ticket stubs, and programs from special events.

Students can then discuss their own posters, and focus on the following questions:

- What can they tell from the poster about themselves as individuals or as a class?
- What role has the community played in their lives?
- How do they think their interactions with the community would be affected by having a birth defect such as Mark's?

Reading

Before class, assign five students to play the roles of Carolyn Motta, Ann

Senatore, David Senatore, Mark Senatore, and Mark Motta. These students should prepare to read aloud the material written by the person they are role-playing.

As each piece is read, give students a chance to air their initial reactions before going on the the next piece or the discussion questions. Have each student do the "Your Views" exercise, and share their ideas before reading the interview with Mark Motta. After reading the interview, have the students once again complete the "Your Views" exercise to see if their feelings about Mark have changed. Then go on to the questions focusing on students' reactions to what Mark says and changes in their perceptions of special-needs people in general.

Discussion

In small groups, discuss the remaining questions, each group taking one question. The groups discussing the first two questions should refer to the transcript, and should list examples of how the Senatores influenced Mark as well as examples of qualities in the Mottas that enable them to accept help. The group discussing a conversation with Mark can refer to Dr. Cooke on "How to Act with People with Special Needs." They should write down specific comments or questions for Mark. The four groups might then report on their discussions to the rest of the class.

The small groups might also focus on community facilities that affect Mark and work from these ideas:

- What does Mark say about adaptations the community should make to meet the needs of handicapped persons? List these ideas.
- Make a list of excursions the Senatores took into the community with Mark (to the submarine base, the restaurant, the beach, the wrestling match.) For each, list the special problems Mark encountered because of cerebral palsy. How did people in the community respond to these problems? What efforts does your community make to accomodate people with special needs? You might fill in a chart similar to this one:

	Special Problems	*How People Responded*
Submarine base		
Restaurant		
Wrestling match		

Mark now lives at a community workshop for adolescents with multiple handicaps. What was difficult about making this move? What does Mark gain from being at the workshop that he could not get at home?

Notes from Dr. Cooke: How to Act with People with Special Needs (30 minutes)

Materials

- Student book, pp. 22
- Supplementary reading, "Notes from a Social Worker (included in the background readings in this guide, pp. 79-80).

Purpose

- To help students learn to look for cues about how to respond to other individuals, including those with special needs.

Procedure

Dr. Cooke's notes should be read by students when they discuss ways to act with Stephen Slater and Mark Motta. If the material was not read during the discussion of these selections, it could be assigned for reading at home at the end of "Helping Others." Recall the "Mirror Image" activity and the "Tips for Listening" discussed in *Families with Special-Needs Children*. Then consider how all of the insights gained thus far help students in their daily interactions.

- Can students recall specific interactions with someone with special needs, especially situations in which these ideas could have been helpful?
- What might they do or say differently the next time?

Notes from a Teacher's Aide (1 class)

Materials

- Student book, pp. 23-24

Purpose

- To consider the special needs of profoundly retarded adolescents and their families, how the community can respond to these needs, and how students themselves might support or help in such community facilities.

Description

This first-person narrative gives students a picture of what happens to children with severe mental and physical disabilities. These children cannot be mainstreamed in public schools. Instead, they attend a special community-based school.

A teacher's aide describes a daily program for students who are 10-20 years old, with motor functions ranging from a 2- to 18-month level. Students will probably be struck by the very basic skills teachers work on, such as toilet training or pulling a toy on a string, and also by the warmth and commitment the teacher feels for each individual student.

Procedure

Read the introduction and the notes in class. Then divide students into small groups to discuss questions and report back to the class. Besides the questions in the student book, groups could discuss the following:

- Each group member could choose one student described in the account, write about this student's special needs, and then describe the personal qualities and teaching techniques that seemed to help that student. Students could then discuss their notes and see how the qualities or techniques noted are similar or different for all students. For example, while warmth and common sense are important in any relationship, there are also some specialized skills necessary for working with special-needs students. In addition, it's important to note that these students are not all the same; like any group, they are unique individuals, with different needs, personalities, and abilities.

- Does your community have any special programs for adolescents with severe disabilities? Report on these for the Yellow Pages. Who do they serve?
- What is their program like? Do you think the community has the responsibility to teach such children? (This question may lead into a discussion of the right of everyone to learn and grow *vs.* the difficulty of helping these children advance even a very small step.)
- Do you think you might want to work in such a program? What might be difficult for you? What would you have to learn? What might be rewarding?

Ellen's Story (1-3 classes)

Materials

- Student book, pp. 25-29
- *Ellen* tape and tape recorder

Purposes

- To consider the specific needs of a child with special needs and that child's adolescent parents.
- To consider the resources available to help any individual with special needs in the students' own community.
- To consider how students themselves can help people with special needs.

Description

This tape is narrated by the adolescent mother of a girl with cerebral palsy. The case study applies students' earlier ideas about how people decide to become parents and what happens when their children have birth defects to the special problems of an adolescent parent of a child with special needs. The questions and activities at the end allow students to summarize their work on the special needs of parents and children with birth defects, community

resources to meet these needs, and how students themselves can respond to these needs. Among the activities are suggestions for beginning and researching projects for the Yellow Pages directory.

Procedure

Introduce Ellen and Cherice and play the tape once while students follow their transcripts. Give students time to air their initial reactions to the tape. Then divide the class into three groups and have them listen to the tape a second time while taking notes on the three points listed in the student book: Ellen's youth, supports she received, and her qualities and coping skills. Give each group time to compile and compare their notes and then have them report to the class.

Activity

The initial listing for this activity might be done first by individual students on forms duplicated from the samples in this guide (pages 67-69). These lists can then be compiled on large forms reproduced on the board or on newsprint. To avoid repetitive activity, the final compiling could be done in three groups (for the needs of Ellen, Cherice, and other parents discussed in the materials) and then presented to the class.

Finally, assign several students to list each community resource on a 3x5 index card or piece of paper under the "need" that it meets. This activity can introduce work on the Yellow Pages directory (see page 72 in this guide). Information that is missing from each card (services provided, ages served, etc.) could be researched by students as part of their larger research project.

Service Projects (ongoing throughout book)

These projects are designed to encourage students to take personal responsibility for the needs of people in their communities with birth defects. Work on these projects can be done in class along with work on Yellow Pages projects. Students should give progress reports to you in writing as well as make a final report to the class.

Name .....

Ellen's needs	Resources Ellen used for each need	Where these resources exist in our community	What I could do to help
During pregnancy:			
Now:			
In the future:			

For which of Ellen's needs could she find no resource?

Name .....

Cherice's needs	Resources Ellen used for each need	Where these resources exist in our community	What I could do to help
Before birth:			
Now:			
In the future:			

Name .....

List other parents in this course or parents you know with children with special needs	List their needs	List resources available to them	Resources in our community that could help	What I could do to help
Jenny MacLean				
Neil and Donna Hobson				
The O'Mally family				
Bill and Margot Kaldma				
Stephen Slater				
Carolyn and Mark Motta				

Helping Ourselves: How Parents Affect the Health of Their Children

This section is designed as a resource to the case studies. It describes how heredity and environment may interact to cause defects. The questions and Yellow Pages research projects in this section direct attention to how students can take responsibility, individually and as members of society, to help prevent birth defects and start healthy families. Included at the end of this guide are step-by-step directions for helping students to compile a directory of community resources for people with special needs.

Learning Objectives

- To consider environmental factors that affect the health of parents and children.
- To provide information on some ways it may be possible for individuals to cut down on the risks of having children with birth defects.
- To encourage students to care for themselves and to prepare for having healthy families.
- To help students understand that they can become effective advocates for social policies that foster healthy babies, healthy mothers, and healthy families.
- To help students understand that the risk of having a child with a birth defect is greater for adolescents than for mothers in their twenties.

Possible Class Sequence (4-6 classes)

Classes 1-2	A Baby's Health is Influenced by...
Classes 3-6	Yellow Pages activity

A New Kind of Checkup (at home reading)

Materials

- Student book, pp.34 -35

Purpose

- To focus attention on one way that female students can begin caring for themselves in preparation for having planned, healthy pregnancies and healthy babies.

Description

This material is in two parts. First an adolescent describes her fears about

going to a gynecologist. Then the mother of an adolescent girl describes why gynecological exams are important and what they are like.

Procedure

Assign this for reading at home, and ask students to turn in written responses to the questions. The reading can be done anytime during work on this section.

Fostering Healthy Growth (2 classes)

Materials

- Student book, pp. 36 - 59

Purpose

- To consider environmental factors that affect the health of parents and children; ways to prevent birth defects; how students themselves can plan for and start healthy families; the role students might play in preventing birth defects throughout society; and to assemble a Yellow Pages of community health resources for people with special needs.

Description

This section provides a time for discussing factors that may affect the health of a baby and cause defects after conception. These include such factors as environmental hazards, drugs, smoking, alcohol, nutrition, prenatal care, family income, low birthweight, and parents' ages. Such factors may interact with the genetic make-up of the fetus and affect the developmental process. The materials emphasize ways in which individuals can positively affect the health of children, particularly the students' own future children.

Procedure

There is too much reading in this section to have each student cover it all in class. One option is to have students read this section at home while they are working on *Families with Special-Needs Children* and *Families and Futures: Helping Self and Others*. The reading can then be discussed in class in one session near the end of the course. An alternative is to divide the reading into sections and assign these readings to small groups in class. You might list the factors presented on the board, have students choose one that interests them, and then divide students into small groups to read, discuss, and write about their topic. The student groups can then report back to the class.

At this point, the teacher might emphasize, as the text does, that all of these factors affect each other. In doing so, you might discuss the possible links between parents' age and nutrition, between income and nutrition, and so on. You might also acknowledge that there is much we don't yet know about the causes and prevention of birth defects. For students who would like further information on some topics, you might duplicate relevant background readings included in this guide.

Questions and Activities
Two kinds of questions are included for discussion with each factor. Some ask for students' thoughts and opinions, while others require research in the community or library.

The questions calling for personal opinion might be discussed by the same small groups reporting on each environmental factor. Some additional questions that might be covered are:

- Consider how, if at all, you can help someone who drinks a lot.
- List foods you like under each of the four major food categories.
- How might the way a woman feels about her body affect how she eats during pregnancy?
- Do you know anyone who is pregnant and is not getting prenatal care? What are some of the reasons?
- Can you think of ways in which the health problems of poor children are of concern to all members of society?

Research Questions for Yellow Pages
Each small group might read the projects suggested in its section and describe these to the class when making its report. List these projects on the board after each group has reported to the class. The projects described after "Ellen's Story" might be listed and assigned at this time as well.

Describe the Yellow Pages and have students individually, in pairs, or in groups, decide which projects they will pursue. Perhaps the same small groups that read about alcohol might regroup to do the research on alcohol. However, some students may prefer to switch groups or topics at this time.

The project work for each environmental factor is not evenly divided. For example, the section on parents' ages has no suggested activities, while the section on income has one main question for research. In contrast, the section on prenatal care suggests several topics to investigate, along with ways of sharing information. You could divide projects from the longer sections among several groups. You might also use this opportunity to individualize the work and give each student the amount of work you think he or she can handle.

Allow one to two weeks for students to complete these projects, working both at home and in class. Decide whether the class wants to organize the Yellow Pages into a card file or notebook. Each group can then record its findings on 5x8 index cards or loose-leaf notebook sheets.

Health Resources Yellow Pages (3 classes or ongoing throughout book)

Students should be aware of this activity during the entire course. Its purposes are to make students cognizant of the kinds of resources available in their community, and the kinds of services each resource provides. The activity is also designed to let students imagine using these resources themselves and/or providing some of these services to others.

Caregiving is an element of this program that will be rewarding to students who are able to give time to it. Working in a classroom of young children, where some or all are handicapped, would be a very meaningful experience for students, as would babysitting for a special-needs child or working as a receptionist in a clinic for children with birth defects.

Projects

Besides the research projects suggested in "How Parents Affect the Health of Children" and at the end of "Ellen's Story," many ideas for projects will come out of the case materials themselves. For example, when discussing Ellen, students will note that they need to find out what resources are available for those afflicted with cerebral palsy in their community. They might also consider what resources are available for retarded adults when discussing Geri.

From the beginning of the course, keep a list of needs that students may want to research. Other ideas for the Yellow Pages will come from students' own friends and families and discussions of their needs, or from newspaper and magazine clippings students collect. Brainstorm other ideas and places to investigate. The list might include:

- Town Board of Health
- Pediatrician for the school department
- Public Works Department (Are there wheelchair ramps in town?)
- Shopping malls (wheelchair ramps? handicapped rest rooms?)
- March of Dimes
- School Department (How are children placed in the public schools? What other schools exist to meet their needs?)
- Nursery schools/day care centers

Getting Information and Planning (1 class or ongoing throughout book)

Some projects tell students whom to call or where to go to search for certain kinds of information; other projects do not. In some cases, students working together might want to brainstorm places to look for the information they need (for example, community agencies, state and local government offices, the library). For additional help, students might ask the March of Dimes, talk to a special education teacher, or look in the telephone book.

Students should have time to plan their projects together in class, listing the tasks involved in gathering information (for example, calling agencies, looking up information in the library, writing for pamphlets, visiting agencies, interviewing a specialist). They should assign tasks to each member of the group and specify a deadline. Lists of tasks and who is responsible for them can then be handed to you at the end of a class planning session.

If students need to write letters (to federal regulatory agencies, for example), they might do this together in class. They could also send away for pamphlets

or government publications in class. At the same time, they might write letters inviting speakers such as an obstetrician or a representative of a consumer advocacy group to class.

Whether students are planning to have speakers in class, to talk to people where they work, or even to talk on the telephone, they should plan these activities and write down their questions ahead of time. They might even role-play their calls or interviews as a group. Such practice sessions can help students feel more confident about talking to strangers, and might also help them recognize if some questions are unclear or don't elicit the information students are really looking for.

When students contact a community resource to get specific information, they are in effect taking the role of parents concerned about birth defects. At the same time, they might learn other things about the resource agency as well, such as whom it serves and what it does. Encourage students to seek out information in as much detail as possible. It is also more beneficial for a student to visit a resource personally, and to take some notes as to his or her own personal reaction to the atmosphere, rather than to telephone or to visit an office simply to pick up printed materials and leave. If students call several agencies before finding the right source for their information, they might still include a brief report on what each agency does offer.

Recording Information (1 class or ongoing throughout book)

Students might record interviews or class speakers on audio tapes or by taking notes on an interview form they develop ahead of time. (While taping leaves the interviewer freer during the interview session, the tapes must still be transcribed and sorted out eventually; this can be very time consuming.) If students choose to tape interviews, they can always go back to the tape and note down items they may have missed when listening to the speaker.

When students read pamphlets or do library research, they should note down relevant information so that it can be organized later. In some cases, students might collect data at home, then write in class. For example, when considering products with harmful substances, they might list household and food products they use, look up their ingredients at home and/or in the library, and then discuss and write in class about the necessity for the product and possible alternatives for it.

Final data can be recorded by topic on 5x8 cards or notebook sheets, depending on the final form the class chooses for the Yellow Pages.

Organizing Information (1 class or ongoing throughout book)

The class must decide how to organize the Yellow Pages (notebook pages or card file) before they classify each topic under a heading. They should consider such questions as: Will the information be organized according to topics in the

student material (in which case some agencies may appear under several headings), or will the Yellow Pages consist of an alphabetical listing of agencies, people, and resource books? Other options may appear, depending on the data gathered by your particular students.

Try to consider each student's ideas about organizing the information. You might write suggestions on the board and discuss the pros and cons of each procedure. Which system would be easiest for someone who needs this information to use?

Once you decide, have each group look over its entries and label them properly. Ask several students to compile the entries, make divider pages or cards, and bind or box them together. Cards that duplicate each other should be combined. Students may use the Yellow Pages themselves and learn more about a resource that interests them. This information can then be added to the appropriate card or sheet.

Sharing and Using the Yellow Pages (ongoing throughout book)

Many projects include ideas for sharing information about specific topics. Students might also consider how they can share the Yellow Pages as a whole. When completed, the card file will be an important and useful community resource. The school or local library might want to keep it on its reference shelf, so that it is available to anyone who might want to use it. If it is thorough enough, it might be duplicated for local community social service agencies, counseling services for teens and parents, obstetricians' offices, or special-needs educators. If your community has an organization for parents of children with birth defects, they might appreciate such a resource survey.

Students can also use the Yellow Pages to do the activities after Ellen's case study, or for service projects they may wish to undertake after completing the work on this course.

Sample Lesson Plan

Two Family Album (2 classes)

End of preceding class: Brainstorm a list of agencies, services, and events in the community that interact with children. Assign students to bring in pictures or papers representing their own interactions with the community.	5 minutes
Day One	
Assemble class poster and discuss.	20 minutes
Present Mark Motta poster. Each student chooses three pictures and writes about questions in guide.	10 minutes
Students writing on same pictures meet in small groups.	5 minutes
Class looks for patterns as Mark grows up.	5 minutes
Day Two	
Read aloud and discuss the material by Carolyn Motta and the Senatores.	10 minutes
Students do "Your Views" activity individually, then share results.	5 minutes
Read and discuss material by Mark Motta.	10 minutes
Discuss the questions in small groups.	10 minutes
Report to class.	5 minutes

Sample Lesson Plan

"A Baby's Health is Influenced by..." (1 class)

List factors (environmental hazards, medications, drugs) on the board and let students choose one topic. — 5 minutes

Divide into groups. Each group:

Reads its section of the student booklet.

Discusses information and questions calling for personal opinion.

Reads accompanying research projects and prepares to describe these to the class. — 20 minutes

Reports to the whole class on the issues they discussed and possible research projects for the Yellow Pages. (List these on the board.) — 15 minutes

Describe the Yellow Pages and have students choose a research project. These may be done by the students individually, in pairs, or in small groups. — 5 minutes

The Glossary

This resource should be useful throughout the course. Whenever students have questions about unfamiliar terms, such as names of specific birth defects or specific factors that cause defects, they can refer to it. Encourage students to refer to the glossary in each book when they have questions while reading at home or when questions arise during class discussion. If students have questions about terms that are not included in the glossary, they might look up these words in a dictionary or encyclopedia and add the terms and their own definitions to the student text.

Background Readings

Notes From a Social Worker

The following notes can deepen students' understanding of several pieces of material. The first paragraphs on parents' anger and needs underlying that anger can help students understand the anger Geri and Carolyn Motta expressed at the lack of help they received from friends and/or professionals. The middle section on how we react to people with special needs complements Dr. Cooke's advice. The last paragraph about "real success in life" can serve as one definition of good mental health.

Geri reported, "There was not one social worker, not one doctor, who said, 'You poor kid....'"

Families of retarded or handicapped children have a difficult time. Family members may get very angry. They may get angry at the doctor or social worker or angry at other people and think they are not really trying to help them. These families are actually feeling very hurt and sad. They are disappointed and feel helpless. These are not feelings they can express easily to other people, so they even have trouble admitting to themselves how sad they are. Instead, they get angry. They go around with a chip on their shoulder. And this makes it especially difficult for people who try to help them and be friendly. Sometimes, the way families respond makes other people feel uncomfortable and guilty. Sometimes, it makes other people feel angry, too.

It's important to realize that these families really do want help and friendliness from other people. If one can just remember why the family acts in such an unfriendly way, one can more easily "hang in there" with them. After a while, the family will usually relax. Then one can see how important being friendly is.

Families may, however, have good reason to be angry. Sometimes other people feel scared and really do act unfriendly. Sometimes, doctors and social workers are not as understanding as they could be. These professionals may just hate having to tell families bad news and thus do so rudely. Professionals may even make mistakes. If a family has a different impression about what's going on with their child, it's important that the family pay attention to that impression. This is hard to do because people tend to think of doctors or other professionals as experts who never make mistakes. Usually the family starts to question their own way of seeing and doing things. But after all, the family is with the child every day. The family knows the child best. It doesn't make sense for the family to just give up its own impressions and ideas without taking a very good look at them. Only after people have really checked out an idea or impression can they decide if it's right or wrong. And sometimes families have to really struggle to get things straightened out.

Perhaps being friendly toward someone who's retarded or handicapped sounds too difficult. It's not easy to watch someone who has trouble getting his body

to work the way we're used to having bodies work. And it's not easy listening to someone who has trouble talking or someone who isn't very smart. It's strange and it's frightening and it makes us feel uncomfortable. It's okay to feel that way, but we don't have to act rudely just because we feel uncomfortable. We can feel all kinds of strange and uncomfortable feelings and still act pleasant and be patient. It's amazing that after a while the feelings of strangeness and discomfort do subside. It's nice to know that we can handle things even when we do feel uncomfortable. (And it's nice to know we don't have to back off from a situation just because we feel uncomfortable.)

Different people have different experiences in life. Some seem to have more bad luck than others, and one often hears the comment that "life isn't fair." This is true! Life isn't fair and there are many things, both good and bad, that just plain happen. There's no reason for it and no one can be either praised or blamed. Some people are seriously hurt in accidents; others just miss being hurt. Some people are born handicapped or have handicapped children in the family; others have no such experience.

What really matters, and what people can have something to say about, is how they handle situations when they come up. If people can confront how they really feel about what's happening, and can talk and listen honestly with other people, they can usually figure out the best plan and the best way to act. This is what the family of a handicapped child has to do. They have to sit down and really talk and listen to each other. Some families find it useful to do this with a counselor present. Because families have so many different kinds of feelings at times like this, it's important that they be polite with each other. There's a difference between talking about feeling angry and acting angry. And just talking about the feelings can be a great relief and usually the anger lets up.

The signs of real success in life are how people get along with and treat other people as well as how they do their jobs. How people love and how they work tells a lot about how successful they are as people. These are the most important measures of good mental health. Loving means treating others decently and being able to expect to be treated decently by them. It doesn't mean that a person has to approve of or even like everything about another person. Work can mean a variety of things. It doesn't mean how much money a person makes or how famous a person is. It means how well the person does the job. For young people in school the job is doing the studies; for the doctor, the job is being a doctor; for the handicapped person, the job might be learning to walk or talk or packing sponges into cellophane wrappings in a sheltered workshop. For the family of a handicapped child, the job of helping the child to learn to walk or talk can be very difficult, but both the family and the child can feel very proud.

Cerebral Palsy

Definition

The term "cerebral palsy," as currently used, includes a group of nonprogressive (stable) disorders resulting from malfunction of the motor centers of the brain, characterized by paralysis, weakness, incoordination or other aberrations of motor function, which have their origin prenatally, during birth, or in the first year or two of life. Cerebral palsy encompasses the neuromotor manifestations of organic brain damage and occurs in conjunction with other manifestations of it such as seizures, mental retardation, various sensory defects, and behavior or emotional disorders. It is not a specific type of brain damage, but it results from congenital defects, mechanical and chemical injury, and infection. It is a nonfatal (per se), noncurable condition that is frequently amenable to therapy and training.

Types of Cerebral Palsy

There are five major types of cerebral palsy:

- **Spasticity:** characterized by the pathologic (disordered) stretch reflex, increased activity of deep tendon reflexes, scissoring (of legs) and contractures affecting the antigravity muscles.
- **Athetosis:** marked by involuntary incoordinate motion with varying degrees of muscle tension; reflexes are usually normal; during second year develops pattern of fine wandering movements of the fingers, hands, and feet.
- **Ataxia:** manifest by lack of coordination due to disturbances of the sense of balance and kinesthesia (sense of body position and movement).
- **Tremors:** may be intentional or involuntary motions with a rhythmic pattern.
- **Atonia or hypotonia:** characterized by soft muscles and (usually) by increased deep tendon reflexes.

Mixed types of cerebral palsy are seen, but usually one form predominates. Spasticity is the most frequent type, which together with athetosis accounts for approximately 75 percent of all cases; seizures occur in approximately 25 percent.

Incidence and Diagnosis

Cerebral palsy is one of the leading causes of crippling in children; it is estimated that the prevalence rate is 100 to 600 cases per 100,000 population, the majority of known patients being under 21 years of age.

When one manifestation of brain damage is recognized, others should be suspected. Children who have a history of any of the factors outlined above should be observed carefully for abnormalities. The presense of any abnormality or of disturbances during the neonatal period, such as feeding problems, irritability or drowsiness, cyanosis (bluish discoloration of the skin), jaundice (yellow discoloration of the skin), respiratory difficulties, abnormal muscle tone, or seizures, should lead to a careful observation of the central nervous system.

The cases of more severe damage are usually apparent early in life; those of less degree should be suspected when there is a significant deviation from normal rates of growth and development or when there is persistence of infantile physiologic reflexes.

Some Aspects of Treatment

The orthopedist is concerned with developing and maintaining good body mechanics. This is accomplished by bracing, by physical therapy, and by surgery that is largely limited to tendon lengthening, to arthrodeses (the connecting of joints), and to muscle transfers in older children.

Training—resulting in functional improvement of body mechanics, muscular control, gait, use of hands, and in verbal communication—can be effectively carried out by parents under the direction of physical, occupational, and speech therapists.

Physiotherapy, most of which can be carried out by the parent (after instruction) should be begun in infancy to avoid development of contractures and to stimulate control of movement.

Prognosis

Prognosis is dependent on a careful appraisal of all factors related to the individual child, his or her family, and the community. In general, the child's intelligence is the best prognostic guide, so that psychometrics (the measurement of psychological variables, such as intellgence, aptitude, and emotional disturbance) should be employed.

*This material has been adapted from *Textbook of Pediatrics*, seventh edition, edited by W.E. Nelson, M.D., D.Sc., pp. 71-73.

Down's Syndrome

Mongolism is the single most common cause of mental retardation. It affects one in approximately 600 babies. Five to 6 percent of all mentally retarded individuals are mongoloids and the disorder accounts for ten to 20 percent of all the retarded who live in institutions in the United States.

Because children with this disorder often have heart abnormalities and because they are particularly susceptible to respiratory disease, most mongoloids used to die before they reached adulthood. One study of mongoloids born in the years 1948-1957 in Victoria, Australia, for example, showed that 25 percent died before the age of six months and 60 percent before age five. Other studies indicate that respiratory infections account for about half the deaths of youngsters with Down's syndrome and congenital heart defects for about one third.

However, widespread use of antibiotics and better ways of treating heart defects have increased the life expectancy of mongoloids considerably. Recent, accurate studies of the life expectancy of these youngsters who survive early childhood are not yet available, but it may approach almost normal. It is known that the total number of mongoloids in this country has quadrupled in the last generation, even though the rate of mongoloid births has not increased.

The name "mongolism" is misleading, for the birth defect to which it refers has no connection with the Oriental race. The tag was originally pinned on this particular disorder by careless observers who thought the characteristic appearance of the eyes resembled that of Orientals. Doctors prefer to call the condition "Down's Syndrome" because it was first described by Dr.Langdon Down in 1866.

It was not until almost a century later, in 1959, that another major clue to Down's syndrome was discovered. In that year, Dr. Jerome Lejeune, Dr. M. Gautier and Dr. Raymond Turpin noted that children with mongolism have 47 chromosomes instead of 46 in most of the cells in their body. The extra microscopic bit of genetic material is an extra #21 chromosome, one of the smallest in the human cell. Most mongoloids have three chromsomes instead of the normal two in the pair labeled #21. That is why the disorder is also called "Trisomy 21."

Why this chromosomal error occurs is also not fully known, but scientists have discovered many challenging clues. Because the abnormal number of chromosomes occurs in all of the cells in a mongoloid's body, scientists know the mistake must take place in the egg or sperm before conception or during the first cell division immediately after fertilization....In most instances, the chromosomal error seems to be directly related to the age of the mother.

---

*This material has been excerpted from *Is My Baby All Right? A Guide to Birth Defects*, Virginia Apgar, M.D., M.P.H., and Joan Beck. New York: Pocket Books, 1972.

Chances of having a mongoloid baby are only one in 3000 for a mother younger than 30 years old. For a mother in the 30-34 age group, the risk is one in 600. One mother in every 280 between the ages of 35 and 39 bears a child with Down's syndrome.

After age 40, the risk of having a mongoloid baby increases sharply. One child in every 80 born to a mother between the ages of 40 and 44 is a mongoloid. And if a woman is older than 44 when she bears a baby, chances are one in 40 the infant will have Down's Syndrome.

Precisely why aging in a mother is related to the kind of chromosomal error found in most children with Down's syndrome isn't fully understood. One study shows that about half of the over-40 mothers who had mongoloid babies were already in menopause. And in more than 90 percent of these women, there had been a long interval between previous pregnancies and the one which resulted in the mongoloid infant. The most likely explanation is that during the long wait before ovulation, the egg cells which give rise to mongoloid babies become so overaged that their cell-division mechanism does not function perfectly, resulting in the chromosome mistake.

Research is also beginning to suggest reasons other than age for the occurrence of an extra chromosome in some instances of Down's syndrome. One study shows a relationship between an outbreak of hepatitis and an increase in the number of mongoloid babies born about nine months later. However, other studies do not corroborate these findings. Several studies have reported that mothers of mongoloid children have received more exposure to radiation, usually X-rays of the abdomen, during their life than mothers of normal babies. Exposure of the father to radar just prior to the conception has also been noted in some instances of Down's syndrome.

Mongoloid births seem to occur in clusters in certain areas of the world and in certain years. No one knows why. But this may point to a virus as somehow triggering the chromosomal error. This virus may cause an infection in the mother so mild she may not even be aware of any symptoms. Much research is now under way to learn more precisely about any possible link between viruses or radiation and mongolism.

Only 2 or 3 percent of mongoloid children have the translocation kind of chromosome mistake, rather than the triple #21 type. The mothers of these mongoloids are in the usual childbearing age range, rather than concentrated in the over-40 bracket. Often, when chromosome studies of these parents are made, it is found that the translocation has been inherited. This is usually the case when more than one mongoloid is found in a family, or among close relatives.

In this unusual, hereditary type of mongolism, one parent—usually the mother—has only 45 chromosomes. Yet she is normal herself, for she has the normal amount of chromosome material. The only difference is that one of her #21 chromosomes is stuck onto an arm of another chromosome, usually a #15. The egg cell that produced the mongoloid baby just happened to contain the stuck-together chromosomes as well as the normal #21. When this egg cell was

fertilized by a normal sperm with a single, normal #21 chromosome, it then contained two normal #21 chromosomes plus the stuck-together #15 and #21, adding up to the disastrous three #21 chromosomes. It is possible for the father's sperm to contain the translocation, but this is rare.

When parents younger than 40 have a baby with Down's syndrome, genetic counselors usually advise them to have chromosome studies made before planning to have another child. A mother who has a translocation has one chance in three in each pregnancy of giving birth to a mongoloid baby, regardless of her age. If it is the father who carries the translocation, chances of having a second mongoloid baby seem to be less.

Translocations do occur spontaneously, for reasons which are not yet clearly understood, in babies born to parents in every age bracket who have completely normal chromosomes themselves. This type of translocation is not inherited and is not nearly so likely to happen again in the same family.

The birth of a mongoloid baby comes without warning to parents and doctors in most instances. There are no signs or symptoms during pregnancy that foreshadow the disorder. Mongolism is usually diagnosed at birth or within a few days afterward, although in unusual instances it may not be noted until several weeks or months later.

Chromosome studies provide the only way of diagnosing Down's syndrome beyond doubt, however....

More than 65 symptoms of Down's syndrome have been listed by physicians. No single child has them all. But most youngsters with mongolism show signs of about two-thirds of them. Almost every organ and every part of the body is either abnormal or underdeveloped.

The characteristic facial and physical abnormalities make mongoloids easy to recognize, In fact, children with Down's syndrome look more like each other than they do other members of their own family.

Molly, for example, looks like a typical mongoloid for several reasons. Her head is short and flat in back and the facial bones are underdeveloped for her age. She has always had an unusually large soft spot on her head, which is slow to close. The curving folds of skin at the inner corners of her eyes that give an Oriental illusion are actually typical of all unborn infants, not only Chinese or Japanese. But they are not a reliable diagnostic sign, for they are often seen in babies who do not have Down's syndrome, particularly in eastern Europe, Russia and Germany. Eye sockets like Molly's, which are smaller than normal and egg-shaped, do suggest mongolism.

Like Molly, almost all mongoloids are shorter and less well developed than other children of their age. Their hands, feet, neck, torso, arms and legs are usually shorter than average. Short little fingers, which sometimes curve inward, are another characteristic. Even the palm prints of mongoloids often bear the mark of their disorder. About two-thirds of mongoloids have what doctors call a "simian crease" or "four-finger line" on one or both hands. This is a single, rather straight line across the upper part of the palm, replacing the usual two found in most normal individuals.

In Molly's case, as in many others, it was an unusual flabbiness and lack of muscle tone that first alerted doctors, just hours after her birth, to the possibility that she might have mongolism. This same lack of muscle tone continues to slow down her physical activities and she has lagged behind normal youngsters in learning how to sit, to crawl, to stand and to walk. Poor muscle tone also shows up in the protruding abdomen so many mongoloid children have and in the common occurrence of hernia.

Heart defects are among the most serious and common abnormalities of mongolism. Many individuals with Down's syndrome have heart murmers and other, more serious cardiac abnormalities are frequent. A wide range of blood vessel problems and circulation deficiencies occur in mongoloids. Even if a heart defect could be corrected by surgery, doctors sometimes advise against the operation because so many other defects in blood vessels may be discovered along with it.

The thyroid gland is usually underdeveloped and functions poorly in mongoloids. So does the pituitary. There are frequent abnormalities in the thymus gland and in the adrenal glands. The liver is likely to contain abnormal amounts of fatty tissue. Eye defects are common and many mongoloids need glasses. The outer ear may be unusually shaped and sometimes hearing is impaired. Teeth may be slow to erupt and poorly formed. Both the skin and mucous membrances are subject to infections and mongoloids are particularly prone to have a runny nose and conjunctivitis.

Sex organs in mongoloid males are underdeveloped. It is rare that a mongoloid male ever fathers a child. But tests do show that occasionally what appear to be normal sperm are present and it is considered possible that a mongoloid male could be fertile.

Mongoloid females do ovulate and menstruate and there are about a dozen cases on record in which they have had children. Approximately half of these offspring have inherited Down's syndrome and half have not, which is what genetic theory predicts when the baby's father has normal chromosomes.

Individuals with Down's syndrome do differ considerably in intelligence, although all of them score below average on IQ measures. How retarded a mongoloid is mentally is not related to physical appearance. Some of the most retarded have few obvious, visible mongoloid characteristics; others, whose features mark them immediately as mongoloid, may have relatively high intelligence.

An IQ of about 50 is average for a mongoloid. Often, a child with Down's syndrome tests at a higher IQ level during the early years of life than after six or seven. Researchers explain that the decline in score does not usually represent a decrease in the level of intelligence, but probably reflects the fact that IQ tests for babies and toddlers rely more on motor development than intellectual skills and that children with Down's syndrome are more handicapped in intellectual areas than in motor development. A decrease may also indicate that children with Down's syndrome do not receive appropriate learning stimulation in sufficient amounts.

At best, individuals with Down's syndrome have IQ's in the 65 to 80 range. Some mongoloids are able to hold a simple, routine job as adults, usually in a sheltered workshop. They are not capable of managing their own lives or maintaining independent homes.

Family Medical Record

The National Foundation-March of Dimes, as part of its comprehensive efforts toward prevention of birth defects, urges everyone to keep a family health record. Scientists are learning more of how inherited traits and environmental factors influence the unborn and the newborn. This makes an accurate family health history valuable in routine medical consultations and as a diagnostic tool for physicians. Your medical record also will be useful in filling out insurance forms, school and travel records.

IMPORTANT TELEPHONE NUMBERS

Physicians:
Dr. _____ _____
Dr. _____ _____
Dr. _____ _____
Dr. _____ _____
Dentists:
Dr. _____ _____
Dr. _____ _____
Pharmacist _____ _____

Police Emergency _____
Fire Emergency _____
Ambulance Service _____
Poison Control Center _____
Health Department _____
Health Insurance Agt. _____
Medicare Information _____
Medicaid Information _____
Local Medical Society _____

FAMILY HEALTH HISTORY

Information about the health of your immediate family can prove helpful in early diagnosis and treatment of diseases that are known either to be genetic or to occur more commonly in some families. Make a note of *any* serious or chronic diseases in your family, with special attention to those listed at the right. It also helps to note the age when the disease first occurred.

Be sure to include:

- Allergies
- Arthritis
- Cancer
- Diabetes
- Epilepsy
- Hearing defects
- Heart defects
- Hypertension
- Mental illness
- Mental retardation
- Obesity
- Tuberculosis
- Visual defects
- Other recurring family diseases

NAME	BIRTH DATE	BLOOD TYPE & Rh	OCCUPATION	DISEASES, ETC.	IF DECEASED, AGE AND CAUSE
HUSBAND					
his father					
his mother					
brothers and sisters					
WIFE					
her father					
her mother					
brothers and sisters					

Designed by The National Foundation-March of Dimes in collaboration with the American Medical Association and Woman's Day.

Reprinted by permission

CHILDREN'S BIRTH RECORD

Be sure to note such details as duration of pregnancy, length of labor, cesarean delivery, use of forceps, newborn respiratory distress, jaundice or birth defects. If you are Rh negative and the child was Rh positive, were you given the Rh vaccine?

NAME	DATE	SEX	WT.	BLOOD TYPE & Rh	APGAR SCORE	HOSPITAL, CITY	PHYSICIAN	DETAILS

INCOMPLETE PREGNANCIES

A complete history includes details of spontaneous or induced abortions, miscarriages and stillbirths. If you are Rh negative and the fetus was Rh positive, it is important to know if you were given the Rh vaccine.

TERMINATION	DURATION	CIRCUMSTANCES	TERMINATION	DURATION	CIRCUMSTANCES

IMMUNIZATION SCHEDULE AND RECORD

The American Academy of Pediatrics recommends that children be immunized and given tuberculin testing according to the immunization schedule below. Vaccine combinations and schedules are improved frequently, however, so that a physician can recommend what is best for you. As each immunization is completed, it should be recorded below.

IMMUNIZATION SCHEDULE

2 months	Diphtheria/Tetanus/Pertussis (whooping cough) vaccine, first shot; polio vaccine, first dose
4 months	Polio vaccine, second dose; DTP
6 months	Polio vaccine, completed; DTP
12 months	Tuberculin test
15-18 months	Rubeola (measles) and rubella (German measles) vaccines; polio booster; DTP booster
4-6 years	Polio booster; DTP booster
14-16 years	Tetanus/diphtheria toxoid (adult form)
Thereafter	Tetanus/diphtheria toxoid every 10 years

IMMUNIZATION RECORD

Enter month and year of completed series, boosters, single immunizatic

IMMUNIZATIONS	CHILD	CHILD	CHILD	CHILD	CHILD	MOTHER	FATHER
DTP completed							
boosters							
polio completed							
boosters							
tuberculin test							
rubeola (measles)							
rubella (German measles)							
mumps							
tetanus/diphtheria toxoid							
other							

PERIODIC PHYSICAL EXAMINATIONS

NAME	DATE	PHYSICIAN/CLINIC	HT.	WT.	BLOOD PRESSURE	FINDINGS, ADVICE OR INSTRUCTIONS

INDIVIDUAL PROBLEMS, MEDICATIONS, ALLERGIES

Note any medications that are taken regularly; any substances that must be avoided for medical reasons; and any allergies.

NAME	CONDITIONS	SPECIAL INSTRUCTIONS OR MEDICATIONS

RECORD OF FAMILY ILLNESSES

List accidents, surgery and illnesses, including chicken pox, mononucleosis, hepatitis, measles, rubella, mumps, strep throat and whooping cough. If there was surgery, specify what was done, and note any history of X-rays, medications and special diet. A record of blood transfusions is vital for a woman who is Rh negative.

NAME	DATE	NATURE OF ILLNESS, INJURY OR SURGERY	PHYSICIAN	OFFICE, CLINIC, HOSPITAL	TREATMENT

HEALTH AND ACCIDENT INSURANCE INFORMATION

NAME	POLICY NUMBER	DATE ISSUED	COMPANY	TYPE OF COVERAGE	PREMIUM	PAYMENTS REC'D	PAYMENTS REC'D

Annotated Bibliography

Texts

Autobiographies and Novels (recommended reading for adolescents)

Axline, Virginia M. *Dibbs in Search of Self.* Boston: Houghton Mifflin, 1964.

A moving account of a severely disturbed young boy and how he is helped through play therapy.

Copeland, James. *For the Love of Ann.* New York: Ballantine Press, 1973.

A diary of the author's perceptions of his autistic daughter, Ann. This is a detailed account of the struggles, frustrations, and determination of parents who reject medical advice to institutionalize their daughter and make the decision to care for her at home. Powerful reading.

Guest, Judith. *Ordinary People.* New York: Viking Press, 1971.

A novel about a troubled adolescent that describes his family life and treatment.

Junker, Karin Stensland. *The Child in the Glass Ball.* Translated by Gustaf Lannestock, New York: Abington Press, 1964.

A narrative by the mother of five children, two of whom were born with brain damage. Boel, the eldest daughter, "lives in a glass ball of isolation and never speaks." With the decision to place this lovely girl in an institution, one experiences with this mother the agony, indecision, and eventual feeling of certainty of the "rightness" of her decision. Mrs. Junker describes with exceptional compassion and tenderness how she dealt with her husband's resistance to the "final indignity" when her fifth child, a son, Anders, is born with brain damage.

Kesey, Ken. *One Flew Over the Cuckoo's Nest.* New York: Signet Books, 1962.

A romantic and chilling story of life on the ward of a state mental hospital.

Killilea, Marie. *Karen.* Englewood Cliffs, NJ: Prentice Hall, 1962.

A somewhat dated but moving story of a girl who has cerebral palsy, written by her mother.

Lindner, Robert. *The Fifty-Minute Hour*. New York: Bantam Books, 1976.

A classic accounting of five cases of psychoanalytic treatment. Especially recommended for adolescents.

Parker, Beulah. *My Language is Me*. New York: Basic Books, 1962.

The case history of David, a severely disturbed 16-year-old boy who has created a "language of self-protectiveness."

Skinner, B.F. *Walden Two*. New York: The Macmillan Company, 1966.

The fictional outline of a modern utopia in which problems of society are solved according to behaviorist principles.

White, Robin. *Be Not Afraid: The Story of a Tragically Afflicted Child and His Stubbornly Courageous Family*. New York: The Dial Press, 1972.

This book describes how parents react when they discover that their eight-year-old son is epileptic. It is about a "stubbornly courageous family" who learn to accept that the retardation of their now 21-year-old son's brain "had become totally irreversible."

Birth Defects Reading—Causes, Prevention, and Treatment

"Be Good To Your Baby Before It Is Born. What to Do and What to Expect During Pregnancy." White Plains, NY: The National Foundation/March of Dimes, 1977.

Straightforward information related in a direct personal style. Print is easily readable and well spaced. An excellent guide for expectant parents.

"Birth Defects: The Tragedy and the Hope." White Plains, NY: The National Foundation/March of Dimes, 1976.

A concept-loaded text filled with scientific facts on detection, treatment, prevention, and counseling presented in an interesting way. Excellent photographs enhance this booklet. Highly recommended.

Nordoff, Paul and Clive Robbins. *Therapy in Music for Handicapped Children*. New York: St. Martin's Press, 1972.

A splendidly illustrated and written exploration by a musical composer-special education team into the therapeutic effects of music on the handicapped. The style is vivid and readable. It contains autobiographical accounts of projects carried out in 24 institutes for the handicapped throughout Europe from 1959-1967. Primary source material makes this a valuable resource book. Explicit illustrations and the stark action photographs of children in

music therapy speak for themselves. This book has broad appeal to musicians, therapists, teachers, and students.

Special Readings on Retardation

Nichtern, Sol, M.D. *Helping the Retarded Child.* New York: Grosset and Dunlap, 1964.

Writing for the professional as well as the layman, Dr. Nichtern attempts to answer the "how, what and why" of retardation. An outstanding feature of this book is a 16-page dictionary defining in simple language the most common conditions associated with retardation. The organization and scope of each section allows a smooth transition from one section to another. Readers can easily pick and choose the sections that interest them most. For example, the section called "Special Interventions" covers behavior modification techniques, music and dance therapy, parent organizations, community resources and programs, and residential care. The selected bibliography is excellent.

A Guide for Parents: Helping Your Child to Grow and Learn. Commonwealth of Massachusetts: Department of Mental Health. January, 1975.

This comprehensive, well-organized, and thoroughly readable manual is a useful resource for anyone connected with the developmentally handicapped. Developmental charts are extensive and informative, and training techniques are general enough to allow great latitude. This manual is merely a guideline and not a rulebook. The manual includes a useful appendix listing locations and services available throughout the commonwealth. Varied bibliography.

David, Henry P., ed. *Child Mental Health in International Perspective.* A Volume from the Joint Commission on Mental Health of Children. New York: Harper and Row, 1972.

This collection of articles presents an almost awesome picture of current trends in mental health fields around the world. As Dr. David points out, the United States can no longer ignore the ideas and concepts of other countries, and these articles confirm this statement twofold. This is not a collection specifically aimed at the professional. Indeed, many articles are geared for young people interested in entering the special education field: for example, "How Child-Care Workers Are Trained in Europe" and "Manpower for Youth." The bibliography is a chapter in itself, and the references on national and regional child mental health services abroad number approximately 35. A fascinating study of world-wide reports on the needs of the disturbed, culturally deprived, and retarded.

Pamphlets

Available from the National Foundation/March of Dimes, Box 2000, White Plains, NY 10602.

"Fast Facts about Sickle Cell Anemia."
Detailed pamphlet examines the facts, presents effects, and explores the areas of research being conducted in this hereditary blood disorder. Contrast of bold red and black print adds to the clarity of this question-answer pamphlet.

"Cooley's Anemia. Birth Defects Prevention."
An illustrated pamphlet in question-answer style covering the "who, what, and why" of this defect, also known as Thalassemia. Contains a capsule explanation of blood and blood cells and the inherent traits of this disorder. Valuable information every individual can profit from, not just expectant parents.

"Tay-Sachs Disease."
Thoughtful study of a disease primarily affecting Central and Eastern European Jews. Detailed account of March of Dimes supported research in the variety of inborn errors of metabolism. Especially recommended for those interested in genetics.

Magazine Articles

Etzoini, Amitor, "Genetic Fix." *Psychology Today*, November, 1973.

Biological traits that are highly undesirable in the present might be essential for our survival if our environment should change. (Author uses example of sickle cell anemia.)

"Population Bulletin: Development and Population Growth." A publication of the Population Reference Bureau, Inc., 1755 Massachusetts Ave., Washington, DC, 20036. Vol. 29, No. 1.

A bimonthly publication concerned with population history. The bulletin discusses tremendous possibilities in every field: nutrition, intelligence, genetic potential, famine, malignancy, blood types, folk customs about food, for example.

Project Director
Ruth N. MacDonald

Project Developers
Judith Asch-Goodkin
John McGannon
Jacquelyn G. Sowers
Sandra A. Stevens

Media Specialist
John McGannon

Researcher-Writers
Ann Hagenstein
Elizabeth Perse
Amy Rubin
Anne Senatore
Theodore Sutton

Community/School Health Coordinator
Kenneth A. Zeno

Project Manager
Jill Marcus

Production Manager
Patricia Marshall Jones

Designer
Suzette Phelps

Paste-Up
Ann Schwartz

Editor
Anne Glickman

Consulting Scholars
Dr. Robert Cooke
President, Medical College of Pennsylvania
Philadelphia, Pennsylvania

Effie O. Ellis, M.D.
Director, Quality of Life Conferences
American Medical Association
Quality of Life Consultant Chicago, Illinois

Dr. Lawrence H. Fuchs
Chairman, Department of American Studies
Brandeis University, Waltham, Massachusetts

Dr. George Goethals
Lecturer on Social Relations
Faculty of Arts and Sciences
Harvard University, Cambridge, Massachusetts

Edward Goodkin, M.D.
Chairman, Union County Chapter
National Foundation/March of Dimes
Assistant Clinical Professor
New Jersey Medical School, Newark, New Jersey

Dr. Neil Macintyre
Professor, Department of Anatomy
Case Western Reserve University
School of Medicine Cleveland, Ohio

Special Consultants
John Crawford, M.D.
Pediatric Endocrinologist
Massachusetts General Hospital
Boston, Massachusetts

Neil Hickey, M.S.W.
Director, Adolescent Social Work Program
Parmenter Health Center
Wayland, Massachusetts

Cynthia Kaufman
Instructor, Department of Biology
Bridgeport College, Bridgeport, Connecticut

Lorraine Klerman, Dr.P.H.
Associate Professor of Public Health
Florence Heller Graduate School for Advanced Studies in Social Welfare
Brandeis University, Waltham, Massachusetts

Charles S. Mahan, M.D.
Associate Professor
Department of Obstetrics and Gynecology
College of Medicine
University of Florida, Gainesville, Florida

Henry L. Rosett, M.D.
Associate Professor of Psychiatry
Boston University School of Medicine
Boston, Massachusetts

Carol Smith, R.N.
Martin Luther King, Jr. Hospital
Los Angeles, California

Teacher Guides
Norma Arnow
Emma Rous
Sandra A. Stevens

Business Services
Robert Hassey
Donna Hagerty
Susan MacDonald
Sami Suleiman

Contributors
Laura Arnow
Betty Berry
Maryann Clancy
Betsy Cole
Walter Cole
Henry Felt
Justin Frost
Margaret Frost
Geraldine Gable
John Grant
Margaret Hess
Marguerite Howard
Doni Johnston
Eleanor Jones
Laurel Jones
Janice Kissner
Sherill Koski
Ronald Kronish
Catherine Krupnick
W. Campbell Leaper
Barbara Lonesome
Bronwyn MacDonald
Peggy McNeil
Jessica Mix
Carolyn Motta
Mark Motta
John O'Connor
Richard Peace
Maria Rainho
Stuart Rist
Deborah Rosene
David W. Robinson
Jill Shestokas
Hannah Silverman
Frank Spitzer
William Tichi
Martha Jane Williamson
Susan Wing
Charles Wright

Trial Test Teachers, 1977
Robert Coyne
William Cullinane
Rick Hawkins
Maureen Marshall

Advisory Board
William H. Carlyon, Ph.D.
Director, Department of Health Education
Division of Scientific Activities
American Medical Association, Chicago, Illinois

Wilbur J. Cohen
Dean, School of Education
The University of Michigan, Ann Arbor, Michigan

Kurt W. Deuschle, M.D.
Mount Sinai School of Medicine of the
City University of New York, New York, New York

Rashi Fein, Ph.D.
Professor of Economics
Center for Community Health and Medical Care
Harvard University, Boston, Massachusetts

Victor R. Fuchs, Ph.D.
Professor of Economics, Stanford University
Professor of Community Medicine, Stanford Medical School, Stanford, California

Elizabeth A. Lee
Staff Associate, Division of Education
American Hospital Association, Chicago, Illinois

Lowell S. Levin, Ed.D., M.P.H.
Associate Professor
Department of Epidemiology and Public Health
School of Medicine
Yale University, New Haven, Connecticut

John S. Sinacore
Special Assistant to the Commissioner on Health and Drug Education, The State Education Department
Albany, New York

EDC School and Society Programs Central Staff

Director
Janet Whitla

Senior Advisor
Lawrence H. Fuchs

Project Directors
Marilyn Clayton Felt
Cheryl Healer
Earle Lomon
Ruth N. MacDonald
Dennen Reilley
Susan Christie Thomas
John Whitman
Nancy Wyner

Family and Community Health Through Caregiving is funded by the W.K. Kellogg Foundation. Major support for this book has been provided by the National Foundation/March of Dimes.

Education Development Center, Inc. (EDC) is a publicly supported, nonprofit corporation engaged in educational research and development.